Mental health and service use of adults with intellectual disability and autism spectrum disorder

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Abstract

Background: Autism spectrum disorder (ASD) affects 20-30% of adults with intellectual disability. This group are vulnerable to mental health problems and poor quality of life. They usually share a common mental health care pathway with adults who have intellectual disability without ASD. However, there is little evidence on whether this is an appropriate approach.

Aim: The thesis aimed to explore differences between those with and without ASD among specialist mental health service users with intellectual disability.

Method: The needs, mental health, behaviour, social functioning and service use of 50 participants with ASD from a specialist mental health service for adults with intellectual disability in South East London were compared with 48 participants without ASD. ASD diagnoses were assessed using the Autism Diagnostic Observation Schedule (ADOS). In addition, anonymised case records provided routinely collected, clinical data on 788 participants.

Results: Participants with ASD consumed fewer services than those without ASD despite having more needs. ASD was a significant predictor of poorer mental health and behaviour. Participants with ASD had poorer social functioning than those without ASD. However, when severe intellectual disability, absence of a psychiatric disorder and needs were taken into account, ASD was not a significant predictor of poorer social functioning.

The rate of clinically diagnosed ASD among specialist mental health services users with intellectual disability was 33.5%. However, there was evidence that undiagnosed ASD and unrecognised ASD behaviours were common.

Conclusion: The mental health, behaviour and social functioning of specialist mental health service users with intellectual disability was poorer for those with ASD and significantly associated with factors that characterise many of these individuals. There appeared to be high levels of undiagnosed ASD and a lack of ASD-specific assessment protocols or care pathways. However, these findings may be limited to the specific service user group sampled. More research is needed to determine whether increased recognition of ASD and improved access to services would lead to better outcomes for adults with intellectual disability who have mental health needs.

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Abbreviations

α	Cronbach's alpha
κ	Cohen's kappa
r	Pearson's correlation coefficient
ADOS	Autism Diagnostic Observation Schedule
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
CANDID	Camberwell Assessment of Need for adults with Developmental and Intellectual Disabilities
CPA	Care Programme Approach
CPN	Community Psychiatric Nurse
CRIS	Case Register Interactive Search
DBC	Developmental Behaviour Checklist
DSM	Diagnostic and Statistical Manual of Mental Disorders
ePJS	electronic Patient Journey System
HoNOS-LD	Health of the Nation Outcome Scale for People with Learning Disability
GP	General Practitioner
ICD	International Classification of Diseases
ID	Intellectual Disability
IQ	Intelligence Quotient
MHID	Mental Health in Intellectual Disability [service]
NHS	National Health Service [of the UK]
NICE	National Institute for Health and Clinical Excellence
SCS	Service Consumption Score
SLaM	South London and Maudsley NHS Foundation Trust
PDD	Pervasive Developmental Disability
SD	Standard Deviation
TPBS	Total Problem Behaviour Score [on the DBC]
WHO	World Health Organisation

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Publications

The following papers have been published or accepted for publication following a process of peer-review. The text of these references is reproduced in Appendix I.

Underwood, L., McCarthy, J., Tsakanikos, E., Howlin, P., Bouras, N. and Craig, T.J. (2012). Health and social functioning of adults with intellectual disability and autism. *Journal of Policy and Practice in Intellectual Disability.* 9(2), 147-150.

Underwood, L., McCarthy, J. and Tsakanikos, E. (2011). Assessment of Co-morbid Psychopathology. In J. L. L. Matson and P. Sturmey (Eds). *International Handbook of Autism and Pervasive Developmental Disorders.* New York, Springer: 287-293.

Underwood, L., McCarthy, J. and Tsakanikos, E. (2010). Mental health of adults with autism spectrum disorders and intellectual disability. *Current Opinion in Psychiatry* 23(5): 421-426.

The following paper is in preparation for submission to Research in Intellectual Disabilities (see Appendix I for a summary):
Tsakanikos, E., Underwood, L., McCarthy, J. and Arshad, S. (In preparation). Psychometric properties of the Health of the Nation Outcome Scale for people with Learning Disabilities (HoNOS-LD): An independent investigation.

The following papers have been peer-reviewed and presented at international conferences:

Underwood, L., McCarthy, J., Tsakanikos, E., Howlin, P., Craig, T.J. & Bouras, N. (2011). Mental health service users with Intellectual Disability & Autism Spectrum Disorders. *Joint Congress of the European Association for Mental Health in Intellectual Disability & IASSID Challenging Behaviour & Mental Health SIRG, Manchester*.

Underwood, L., McCarthy, J. and Tsakanikos, E. (2010). Mental health of adults with autism spectrum disorders & ID. *Journal of Applied Research in Intellectual Disabilities [Abstracts of the Third International Conference of IASSID-Europe, Rome]* 23: 421.

McCarthy, J., Underwood, L. and Tsakanikos, E. (2010). Mental Health of Adults with Intellectual Disability and Autism. *National Association of Developmental Disorders (NADD) International Congress, Toronto*.

Underwood, L., McCarthy, J., Tsakanikos, E., Howlin, P., Craig, T.J. and Bouras, N. (2009). Mental Health Outcomes and Service Use of Adults with Learning Disability and Autism. *European Association of Mental Health in Intellectual Disability (EAHMID) Congress, Amsterdam*.

Chapter 1: Introduction and background to the thesis

Introduction

Summary

The thesis is about the impact of autism spectrum disorder (ASD) on adults with intellectual disability who have mental health problems. The study focuses on individuals who are receiving specialist mental health services for adults with intellectual disability. The assessment and prevalence of intellectual disability, ASD and mental health problems are discussed along with service use and intervention. The thesis is supported by two clinic-based, cross-sectional studies that compared participants who have intellectual disability with and without ASD.

Outline of thesis

The thesis begins with a review of the literature relevant to the mental health and service use of adults with intellectual disability and ASD (Chapters 2 to 5). Existing research is used to develop the research questions and hypotheses for the project (Chapter 6). The methods used for the research components of the study are described and followed by the results (Chapters 7 to 12). Finally, the findings are discussed in relation to what was previously known in this area, how the study adds to the evidence base and the implications of the findings for future research and clinical practice (Chapter 13).

Terminology

The thesis uses terminology as described below. Definitions and diagnostic criteria for intellectual disability and ASD are described in the background section and Chapter 2. Throughout the thesis, the term *specialist mental health service users with intellectual disability* is used to describe the users of specialist mental health services that are provided specifically for adults with intellectual disability.

Intellectual disability

Intellectual disability is used in the thesis as an equivalent to *learning disability* (used by services in the UK; Simpson, 1995) and *mental retardation* (currently used in diagnostic criteria; APA, 1994; WHO, 1992). Some people also use the term *learning difficulty* (Department of Health, 2001b). The term intellectual disability is widely used in the international scientific literature and distinguishes the diagnosis from specific learning disorders such as dyslexia. In tables and figures, the abbreviation **ID** is used. Severity of intellectual disability refers to whether an individual has mild, moderate or severe/profound intellectual disability.

Autism spectrum disorder

The abbreviation **ASD** (Autism Spectrum Disorder) is used to describe a group of conditions that current diagnostic criteria call *pervasive developmental disorders* (PDD; APA, 1994; WHO, 1992). In addition to childhood autism and autistic disorder, ASD includes high-functioning autism, Asperger syndrome, atypical autism and PDD-not otherwise specified (PDD-NOS). Different groups and individuals also use *autism spectrum conditions*, *autistic spectrum difference* or *neuro-diversity* and often *autism* is used as an umbrella term for these (Department of Health, 2010b). The thesis uses ASD for all individuals with an autism spectrum disorder and **autism** for those with the specific diagnoses of childhood autism or autistic disorder.

Background

Intellectual disability and ASD are distinct but related conditions that can occur separately or together. They are not mental health problems but individuals with intellectual disability and/or ASD may experience additional psychopathology.

Intellectual disability

Intellectual disability is a developmental disorder characterised by impairments in intelligence and social functioning (Department of Health, 2001b). The most common cause is 'unknown'; accounting for around 30-50% of cases (Bhate & Wilkinson, 2006). However, there are many known genetic, biological and environmental causes (Matilainen et al., 1995).

As the label suggests, intellectual disability is a lifelong disorder. Although improvements in individuals' IQ, skills and functioning can occur over time or as a result of intervention, there is no 'cure' (Beadle-Brown et al., 2000). Most people with intellectual disability in the UK live within the community (Kozma et al., 2009). Current policy focuses on independence, choice, citizenship and social inclusion with an emphasis on person-centred and people first approaches (Department of Health, 2006b; 2007b).

Depending on the severity of their impairment, individuals with intellectual disability are likely to need support throughout or at some point during their lives (Schalock et al., 2010). It has been established that as a group, people with intellectual disability require a high level of service input and that the amount of resources needed to provide health and social care for them is increasing (Emerson & Hatton, 2008; Emerson, 2009; Strydom et al., 2010). However, the actual costs of intellectual disability to the economy are not well understood (Romeo & Molosankwe, 2010).

In the UK, service development has been heavily influenced by the Mansell Committee report (Department of Health, 1993). Developments in policy on health and social care culminated in the publication of *Valuing People* and *Valuing People Now* (Department of Health, 2001b; 2009c). There are guidelines specifically about the provision of mental health services for people with intellectual disability including the *Green Light Toolkit* (Foundation for People with Learning Disabilities, 2004). Despite a growing culture of inclusion and drive for access

to mainstream services, people with intellectual disability are often not mentioned or included in important mental health policy documents (e.g. National Service Frameworks and National Institute of Health and Clinical Excellence (NICE) Guidance).

Autism spectrum disorder

ASD is *"A lifelong condition that affects how a person communicates with, and relates to, other people."* (Department of Health, 2010b; pp. 10). People with ASD often have restricted interests and fixed routines, they may also experience sensory under- or over-sensitivity (Emerson & Baines, 2010).

Autism is a relatively new concept; it was only added to diagnostic manuals in 1980 (APA, 1980). The word itself was coined in 1910 and the disorder *infantile autism* first described in the 1940s (Kanner, 1943; Kuhn, 2004). Since then the definition and classification of autism has expanded and developed into a group of 'pervasive developmental disorders' (PDD) that include Asperger syndrome and atypical ASD (WHO, 1992).

These disorders are said to form a spectrum because although all individuals with ASD have difficulties in social communication, interaction and imagination their functioning is affected in different ways (Department of Health, 2010b). It is common, for people with ASD to be referred to as either low- or high-functioning. This can be seen as equivalent to those with and without intellectual disability but is not a diagnostic classification (Knapp et al., 2009; National Audit Office, 2009b).

ASD is a neurodevelopmental condition that has no known prevention or cure. A single cause has not been identified but there appear to be a number of genetic components to the aetiology of ASD (Sokol & Lahiri, 2011). Some chromosomal conditions are associated with a broader autistic behavioural phenotype although not all individuals will meet the criteria for ASD

(Piven et al., 1997). These include phenylketonuria, tuberous sclerosis, Fragile X and Turner's syndrome (Medical Research Council, 2001).

There is evidence that adult outcome for individuals with ASD is generally poor, whilst burden on carers is often high (Hare et al., 2004; Howlin et al., 2004). However, despite a great deal of interest in children with ASD, until recently there has been relatively little research on adults with ASD (Barnard et al., 2001; Brugha et al., 2009b; Lunsky et al, 2009; Matson & Boisjoli, 2008; Totsika et al., 2010).

The economic cost of ASD in the UK is estimated to be around £28 billion a year (Knapp et al., 2009). The vast majority of this sum (£25 billion) comes from supporting adults with ASD. Concern in the UK about service provision for these individuals has been highlighted by the Department of Health (2006; 2009a; 2009b) and the National Audit Office (2009). Reports from these bodies conclude that current knowledge is lacking with regards to the number of people with ASD using services, the needs of people with ASD and the effectiveness of service provision.

In the UK, significant changes in policy and legislation have taken place in the last two years with the passing of the Autism Act, 2009 and subsequent implementation of the Autism Strategy (Department of Health, 2010b). A clinical guideline on the recognition, referral, diagnosis and management of ASD in adults undergoing a consultation process and is due to be published in June 2012 (NICE, 2012).

People with intellectual disability and ASD

It is common for intellectual disability and ASD to co-occur. The rate of comorbidity appears to increase with the severity of each disorder (Matson & Shoemaker, 2009; Saemundsen et al., 2010). There are shared elements in the diagnostic criteria for severe intellectual disability

and autism including cognitive impairment and communication difficulties (Matson et al., 2008a).

Mental health of adults with intellectual disability and ASD

People with intellectual disability are at increased risk of mental health problems compared to the general population (Cooper & van der Speck, 2009). There is evidence that individuals with ASD are also at higher risk; although most studies have been on children and adolescents (Bradley & Bolton, 2006; Matson et al., 2010). In a survey of psychiatric morbidity in the UK, there was no evidence that adults with ASD received more services for mental or emotional problems compared with the general population (Brugha et al., 2009b). It is not currently clear whether adults with intellectual disability and ASD are at further increased risk of mental health problems than those with one condition or the other (Underwood et al, 2010).

A recent review of the literature specifically on the mental health of adults with both intellectual disability and ASD identified only 14 reports from eight research groups (Underwood et al., 2010). Two were on the development of mental health assessment tools for adults with intellectual disability and ASD (Helverschou et al., 2009; Matson & Boisjoli, 2008). The others focussed on the prevalence of psychopathology in adults with intellectual disability and ASD. In all of these studies there were issues concerning the diagnostic methods used (for ASD and for psychiatric disorder) (Underwood et al., 2010). They also varied according to whether age, severity of intellectual disability and gender were controlled for and which other variables – such as place of residence – were taken into account (La Malfa et al., 2007).

Few of these studies looked beyond clinical psychiatric diagnoses to see where there were any differences in mental health and social functioning of those with and without ASD. Nor was service use investigated in any depth although medication did feature.

Conclusion of the background to the thesis

There are similarities between intellectual disability and ASD and a great deal of crossover in their prevalence but they present distinct challenges for individuals, carers and service providers. There is a lack of research on the provision of services for individuals with intellectual disability and ASD who have additional mental health problems. It is important that studies include the full range of individuals who form this heterogeneous group; across gender, age, ethnicity, severity of intellectual disability and type of ASD.

Chapter 2: Recognition and assessment of intellectual disability, ASD and comorbid mental health problems

Effective recognition and assessment of intellectual disability, ASD and mental health problems is key to successful clinical intervention and service provision (National Audit Office, 2009b). It underpins the ability of researchers to accurately estimate prevalence, identify patterns of comorbidity, evaluate intervention and measure outcome. It is becoming increasingly important to demonstrate that clinical or administrative diagnoses are supported by standardised assessment using evidence-based tools (Lord, 2010; Medical Research Council, 2001; NICE, 2011).

Diagnosing mental and developmental disorders is a challenging process even for the most experienced clinician (Goldberg & Murray, 2006). Central to making an accurate diagnosis is determining whether an individual's symptoms meet diagnostic criteria and ruling out a differential diagnosis (Royal College of Psychiatrists, 2009a). Standardised methods and tools have been developed to aid this process.

This chapter covers the assessment of people with intellectual disability, ASD and comorbid mental health problems. The availability of standardised instruments is reviewed. Many of the diagnoses referred to are based on DSM-IV and ICD-10 criteria (APA, 1994; WHO, 1992). New versions of these manuals due to be published in 2013 and 2015 respectively (see pages 21 and 25).

Recognition and assessment of intellectual disability and ASD

Intellectual disability and ASD are not single disorders with clear aetiology (Matilainen et al., 1995; Medical Research Council, 2001). They are ways of describing and categorising individuals based on their behaviour and, in the case of intellectual disability, deficits in their

cognitive development (Tylender et al., 2007). As such there are no diagnostic tests that can determine categorically whether or not a person has intellectual disability or ASD (Lord & Bishop, 2009; WHO, 1996).

Recognition and assessment of intellectual disability

Recognition and diagnosis of intellectual disability usually takes place during childhood. Eligibility for adult intellectual disability services is often initially based on whether an individual was recognised as having special educational needs or whether they were recognised as having intellectual disability by children's services (see www.improvinghealthandlives.org.uk/about/definition). Psychometric assessment may be required to confirm eligibility.

Diagnostic criteria for intellectual disability

The psychiatric criteria for intellectual disability used in this thesis are clearly defined and have remained stable over time. Intellectual disability is classed as a mental and behavioural disorder in ICD-10 (WHO, 1992) and a developmental disorder on Axis II of DSM-IV (APA, 1994).

Intellectual disability is described as:

"A reduced level of intellectual functioning resulting in diminished ability to adapt to the daily demands of the normal social environment." (WHO, 1992; pp.177).

ICD-10 and DSM-IV state that an individual should have impairment in areas of adaptive behaviour skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. This is generally supported by evidence that the individual has an Intelligence Quotient (IQ) score of less than 70 (APA, 1994; WHO, 1992). However, it is acknowledged that low IQ alone is not sufficient

for assessing an individual's eligibility for intellectual disability services (Department of Health, 2001).

Intellectual disabilities are categorised as mild, moderate, severe and profound; quantified by ICD-10 as IQ scores of 50-69, 35-49, 20-34 and below 20 respectively (WHO, 1992). Intellectual disability can co-occur with any other diagnosis or diagnoses within ICD-10 criteria (although it can be an exclusionary criteria for some language disorders; WHO, 1992).

The publication of new diagnostic criteria could see major changes to the classification of intellectual disability and development disorders including ASD (Andrews et al., 2009). In DSM-5 these will now be grouped together under neurodevelopmental disorders. The term mental retardation will be replaced by intellectual disability which will be classed as an intellectual developmental disorder. Other changes to intellectual disability severity criteria and coding by IQ level are currently unclear (APA website, 2011). The term intellectual developmental disorder will also be used by ICD-11 as a replacement for mental retardation. This category will be relocated under neurodevelopmental disorders (Salvador-Carull et al., 2011).

In practice, working or 'administrative' definitions of intellectual disability continue to vary within and between countries, disciplines and services (Holland, 2011; Sturmey, 1999). In the UK the range of terms that refer intellectual disability include learning disability, learning difficulty and mental impairment (Northfield, 2004). These differ between legislation (e.g. Mental Health Act 1983, Sexual Offences Act 1956 and Police & Criminal Evidence Act 1984) and government departments (e.g. Department for Work & Pensions, Local Authorities that provide social care for adults with disabilities, Department for Education and Department of Health).

This heterogeneity in terminology and definition can make it difficult to determine whether service users or research participants described as having intellectual disability really belong to the same group unless eligibility criteria are explicitly stated.

Assessment of intellectual disability

The assessment of intellectual disability in adults is relatively uncommon since most individuals are expected to have received a diagnosis in childhood. However, there is evidence that mild intellectual disability remains under diagnosed particularly among those not accessing services (Clarke & Griffiths, 2008; Cooper et al., 2007; Department of Health, 2001b). Settings where screening for intellectual disability may be particularly useful include prisons and mental health services (Hayes, 2002; Søndenaa et al., 2008).

A diagnosis of intellectual disability is usually made by specialist psychologists and intellectual disability psychiatrists. The most widely used assessment tool for adults is the Wechsler Adult Intelligence Scale (WAIS; Wechsler, 2008). This produces a range of scores including full scale IQ, performance IQ and verbal IQ (WAIS III; Wechsler, 1997). Other tools that provide evidence on level of functioning and skills include adaptive behaviour scales (ABS) such as the Adaptive Behaviour Assessment System–II (ABAS–II; Harrison & Oakland, 2003), American Association of Mental Retardation ABS (AAMR, 1992), Scales of Independent Behavior (SIB-R; Bruininks et al., 1996) and Vineland-II ABS (Sparrow, 2005). These tools can also be used to estimate severity of intellectual disability. They provide a greater range of information on behaviour and daily living skills. As such they are more widely used in research than standard psychometric tests (Beail, 2003).

Sometimes a measure of need is used as a proxy for an assessment of ability or cognitive development. There is an argument that service eligibility and provision should be based on need rather than fulfilment of diagnostic criteria (McKenzie & Paxton, 2006). Assessment

tools for people with intellectual disability include the Camberwell Assessment of Need for adults with Developmental and Intellectual Disability (Xenitidis et al., 2003), Inventory of Client and Agency Planning (Bruininks et al., 1984) and Supports Intensity Scale (Thompson et al., 2004).

Much research on intellectual disability relies on existing clinical or administrative diagnoses (Maulik et al., 2011). This could be because the reliability and validity of clinical diagnoses are taken for granted since services for adults with intellectual disability are well established. In summary, there is no consensus on the 'gold standard' assessment for intellectual disability apart from clinical judgement supported by psychometric tests and a standardised measure of adaptive functioning (Schalock et al., 2010; Verri et al., 2004).

Recognition and assessment of ASD

Signs of ASD may be observed in children as young as 12 months old. However, a formal diagnosis is not usually made until at least three years of age (Filipeck et al., 1999; Ozonoff et al., 2010; Medical Research Council, 2001). The average age of diagnosis is around 6 years old for autism (Andrews et al, 2009) and around 11 years old for Asperger syndrome (Howlin & Asgharian, 1999; Levy et al., 2009).

Since ASD is a relatively new concept and wider criteria were not introduced until 1994 (in the case of the DSM; APA, 1994) it is common for older individuals to remain undiagnosed in adulthood (Brugha et al., 2011; National Audit Office, 2009a). It is recommended that diagnoses should always be carried out by multi-disciplinary professionals with specific expertise in the assessment of ASD (NICE, 2012). However there are a lack of clinicians with this specialist training (National Audit Office, 2009b). Therefore, few individuals receive comprehensive diagnostic assessment and the identification rate of ASD in the general population is estimated to be as low as 1-4% (National Audit Office, 2009a).

There is debate on the stability of ASD symptoms over time (Matson et al., 2008b; Seltzer et al., 2003). It is thought that most individuals who receive a diagnosis in childhood will meet the criteria for ASD as adults (Billstedt et al., 2005). However, studies have reported improvements in functioning and behaviours, particularly in high-functioning ASD (Esbensen et al., 2010; Marriage et al., 2009; Piven et al., 1996). The strongest predictors of adult symptoms of ASD appear to be childhood IQ and speech before five years of age (Billstedt et al., 2007). If services are to be needs rather than diagnosis driven it may be useful to reassess ASD symptoms across the lifespan particularly for those diagnosed early in childhood (Bennett et al., 2005).

Diagnosing ASD in adults with severe and profound intellectual disability is known to be particularly problematic. There are many overlaps between their characteristics and features of ASD, particularly with regards to communication, imagination, restricted behaviours (Bhaumik et al., 2010; de Bildt et al., 2003; de Bildt et al., 2004; Matson et al., 2007b). It is not clear whether this leads to under- or over-diagnosis of ASD among adults with severe intellectual disability. Identifying effective standardised assessments for this group is more difficult (NICE, 2012).

Diagnostic criteria for ASD

The core clinical features identified by Kanner (1971) remain at the cornerstone of the characterisation of people with ASD which is currently classed as a disorder of psychological development in ICD-10 (WHO, 1992) and a clinical disorder on Axis I of DSM-IV (APA, 1994).

The psychiatric diagnostic criteria for ASD are still evolving (Filipeck et al., 1999). There are discrepancies between different criteria over which disorders are included and what these disorders are called (APA, 1994; WHO, 1992). However, the ‘triad of impairments’ that

describe the core characteristics of ASD consistently form the basis of the definition and diagnostic criteria for ASD (Bhaumik et al., 2010).

The ICD-10 definition of ASD is: *"The presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour."* (WHO, 1992; pp.198).

Despite the known overlaps in the prevalence of intellectual disability and ASD there can be a degree of diagnostic overshadowing that results in one these conditions being overlooked in the presence of an existing diagnosis of the other (Matson & Shoemaker, 2009; Murphy et al., 2011). The diagnostic criteria for ASD are the same for individuals with and without intellectual disability although the diagnosis of a specific ASD may take into account evidence of accompanying intellectual impairment (Royal College of Psychiatrists, 2001a; Saemundsen et al., 2010).

Unlike intellectual disability, according to ICD-10 and DSM-IV, there are several diagnoses that cannot co-occur in an individual with ASD. The most commonly cited example is that ASD currently forms part of the exclusionary criteria for attention deficit hyperactivity disorder (ADHD). Differential diagnoses that should be considered are other developmental language disorders, schizophrenia, schizoid personality disorder, intellectual disability and oppositional defiance disorder (Filipeck et al., 1999).

Aligning diagnostic criteria and clarifying issues of exclusionary diagnoses are one of the key aims of DSM-5 and ICD-11 (Sartorius, 2010). In DSM-5, *autism spectrum disorder* will replace the term pervasive developmental disorders (PDD). It will include "*autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder*

not otherwise specified" (APA website, 2011). There will be a single label of ASD with one set of diagnostic criteria. In addition, the 'triad of impairments' will be amended to two domains: 1) social/communication deficits and 2) fixated interests and repetitive behaviours. It appears that levels of ASD severity will be introduced based on the level of support required by an individual (APA website, 2011). It is thought that ICD-11 will also replace the label PDD with ASD; less is known about changes to the actual diagnostic criteria.

Assessment tools for ASD

A large number of ASD screening tools have been developed. These include the Autism Behavior Checklist (Krug et al., 1980), Autism Spectrum Screening Questionnaire (Posserud et al., 2008), CHecklist for Autism in Toddlers (Dumont-Mathieu & Fein, 2005), Child Autism Rating Scale (Schopler et al., 1980), Gilliam Autism Rating Scale (Gilliam, 1995) and Social Communication Questionnaire (SCQ; Berument et al., 1999).

A smaller number of tools have been developed for adults including the ASD in Adults Screening Questionnaire (ASDASQ; Nylander & Gillberg, 2001) and Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001). The Pervasive Developmental Disorder in Mental Retardation Scale (PDD-MRS; Kraijer & Bildt, 2005) and ASD Diagnosis for Adults Assessment (ASD-DA; Matson et al., 2007a; 2008b) were designed specifically for adults with intellectual disability.

The AQ was designed to screen for high-functioning ASD and Asperger syndrome in adults (Baron-Cohen et al., 2006) A shortened version – the AQ20 was recently used in a study on the prevalence of ASD in the UK (Brugha et al., 2009b). The authors of this study considered the AQ to be the most reliable and valid self-report tool available (Brugha et al., 2009a). The AQ and AQ20 are self-rated and as such are only suitable for adults with high-functioning ASD.

Table 2.1 describes selected assessment tools that may be suitable for adults with intellectual disability.

Table 2.1: Characteristics of selected ASD assessment tools

	Type of tool	Outcome	Diagnostic criteria	Population
ASDASQ	Screening questionnaire (clinician completed, 10 items rated 0 or 1)	Total score (0-9) ≥5 indicates probable ASD	Unclear	Adults
ASD-DA	Diagnostic scale (informant interview, 31 items rated 0 or 1)	Total score (0-31) ≥19 indicates ASD	DSM-IV-TR & ICD-10	Adults with severe & profound ID
PDD-MRS	Screening questionnaire of current behaviour (clinician completed, 12 items)	Total score (0-19)≥10 indicates ASD	DSM-III-R	Adults & children with ID
SCQ	Screening questionnaire of current & lifetime behaviour (informant completed, 40 items rated 0 or 1)	Total score (0-39) ≥15 indicates ASD, ≥22 indicates autism	ADI-R (DSM-IV & ICD-10)	Children & adults
ADI-R	Diagnostic interview with informant (93 items , 1.5-2.5 hours)	Diagnostic algorithm: autism. Current Behavior Algorithm	DSM-IV & ICD-10	Children & adults
ADOS	Diagnostic observation assessment (28-31 items, 45 minutes)	ADOS diagnostic classification: autism, ASD or no ASD	DSM-IV & ICD-10	Children & adults
DISCO	Diagnostic interview with informant	Specific ASD diagnoses according to diagnostic criteria	DSM-IV & ICD-10. Plus Wing & Gould, Kanner, Gillberg	Children & adults
3Di	Computerised diagnostic interview with informant (90 minutes)	ICD-10 criteria for autism, atypical autism, AS or PDD	ICD-10	Children

AS=Asperger syndrome

The ASDASQ was designed for use among adult psychiatric outpatients (Nylander & Gillberg, 2001). In was a study on the prevalence of ASD in Taiwan, it was found to have good validity and test-retest reliability but only fair inter-rater reliability (Chang et al., 2003). An older version (the Nylander questionnaire) was found to have good inter-rater reliability, no false negatives but a high number of false positives, however the sample size of this study was small (Ferriter et al., 2001). The ASDASQ is completed by a clinician, based on their observations of an individual's behaviour.

The PDD-MRS was developed to cover the full range of ASD, intellectual disability severity and ages (Kraijer & Bildt, 2005). It was first tested in a population screening study of Dutch children (de Bildt et al., 2003) and compared with the Autism Behavior Checklist (ABC;

Krug et al., 1980), Autism Diagnostic Interview (ADI-R; Lord et al., 1994) and Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000). The PDD-MRS had high sensitivity but low specificity and only moderate agreement with the ABC (de Bildt et al., 2003). The PDD-MRS has been used to explore the prevalence of ASD and other psychiatric disorders among adults with intellectual disability in Italy (La Malfa et al., 2004; 2007) and England (Morgan et al., 2002; 2003). The PDD-MRS is designed to be completed by a clinician based on their observation of an individual's current behaviour.

The ASD-DA was designed for and tested on adults with severe and profound intellectual disability in residential settings. Several studies were published on its development, psychometric properties and the relationships between ASD symptoms, IQ and challenging behaviours (Matson et al., 2007a; 2007c; 2008a; 2008b; 2008c; Matson & Rivet, 2007; Rojahn et al., 2010; Wilkins & Matson, 2008). However it goes not appear to have been used outside of this research group.

There are four diagnostic assessments tools for ASD: the ADOS, the ADI-R, the Diagnostic Interview for Social and Communication Disorders (DISCO; Billstedt et al., 2007) and the Developmental, Dimensional and Diagnostic Interview (3Di; Skuse et al., 2004). All were originally designed for diagnosing ASD in children although they have been adapted for use with adults and those with intellectual disability (Nebelschwalm & Matson, 2008).

All of these tools were developed to provide item scores that feed into algorithms with cut-off scores for a diagnosis of ASD and/or autism based on DSM-IV or ICD-10 criteria (see Table 2.1). In addition, the DISCO has algorithms that directly relate to Early Infantile Autism (Kanner & Eisenberg, 1956), Asperger syndrome according to Gillberg et al. (2001) and ASD/social impairment according to Wing & Gould (1979). The 3Di includes algorithms for

a number of other ICD-10 psychiatric diagnoses. In addition to these measures, Gillberg et al (2001) developed the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI). However, this does not relate to DSM or ICD-10 criteria for Asperger syndrome.

The ADI-R, 3Di and DISCO are structured interviews with an informant whereas an ADOS assessment involves observation of and interaction with the person being assessed. The ADOS includes a module designed specifically for adults although it requires them to be verbally fluent. The modules for those with phrase or no speech were developed for children rather than non-verbal adults (Berument et al., 2005).

The ADI-R and 3Di rely on an informant who can provide information on a person's developmental history to determine whether the behaviours described started before they were three years of age as required by diagnostic criteria. This can be difficult to establish when assessing adults. Criteria designed specifically for adults with intellectual disability remove this requirement (DC-LD; Royal College of Psychiatrists, 2001a & DMID; Fletcher et al., 2007). However, the diagnostic algorithm for the ADI-R and 3Di are all based on early developmental history and it is not clear whether they can be adapted to accurately diagnose ASD when there is little or none of this information available. All of these diagnostic measures require considerable resources in terms of training, equipment and the time they take to administer (de Bildt et al., 2004; Murphy et al., 2011).

Evidence on the best ways to assess adults with intellectual disability for ASD is weak; largely because studies tend to focus on autism in children rather than the full range of ASD across the lifespan (Stoesz et al., 2011). Many tools were developed for and tested on groups that included people with intellectual disability but there are often no specific norms for them (Kraijer & Bildt, 2005).

The effect of ASD screening tools on treatment and outcome was reviewed recently (Livanis & Mouzakitis, 2010). Three instruments were reviewed but no evidence on their treatment validity was found. Norris and Lecavalier (2010) reviewed five carer-completed screening scales. They identified 20 studies on these tools; most were on the SCQ which the authors described as performing well. There was limited research on other measures and little evidence on their validity for those with low-functioning ASD. The SCQ appears to be the ASD screening tool that has been most tested including studies across a range of ages and intellectual functioning (NICE, 2011).

Newer technologies may be able to play a role in the process of diagnosing ASD. These include neuro-imaging and genetic testing (Ecker et al., 2010). Research on these techniques is at a very early stage and more studies are needed before their effectiveness can be confirmed (NICE, 2011; NICE, 2012).

The forthcoming NICE guideline for ASD in adults systematically evaluated screening tools. The ABC and SCQ were the only tools appropriate for use across the full range of intellectual functioning that met the inclusion criteria (NICE, 2012). The PDD-MRS was also included as a tool for use with adults who have intellectual disability but the review recognised that data on its accuracy was limited and that it is a clinician-rated rather than carer-rated instrument.

A study comparing the ADI-R, ADOS and DSM-IV criteria found a fair level of agreement between the ADI-R and ADOS (de Bildt et al., 2004). This may indicate that a combination of these assessments is more effective than the use of either in isolation (de Bildt et al., 2004). It not clear whether the ADI-R or ADOS can be used to assess individuals with profound intellectual disability (Kraijer & Bildt, 2005).

The ADOS is the only standardised diagnostic assessment that requires direct contact and observation of the individual being assessed for ASD. Most assessment tools used for adults with intellectual disability and ASD (including all the identified screening tools) rely on informant-derived data. It is also the only measure able to indicate presence or absence of ASD without the need for any information on a person's developmental history. Given this it would appear to be the most suitable diagnostic assessment for use with adults who have intellectual disability.

The NICE Guidelines for ASD in adults were unable to draw any conclusions on the best methods of screening for ASD. However, for a standardised diagnostic assessment of ASD in adults with intellectual disability, the ADOS was recommended (NICE, 2012).

Conclusion on the recognition and assessment of ASD

There is great concern about the under recognition of ASD and evidence that increasing identification would lead to improved outcomes and lower costs to the economy (National Audit Office, 2009a). Although there are a great number of assessment tools available, the evidence for their effectiveness is weak.

It is becoming less acceptable for studies on people with ASD to rely on clinical diagnoses without confirmation using standardised tools. This is in part because there is a lack of qualified experts who are capable of carrying out diagnostic assessment. The ADOS and ADI-R are considered the 'gold standard' diagnostic methods for both research and clinical practice (Berument et al., 1999; Bradley & Bolton, 2006; La Malfa et al., 2007; Medical Research Council, 2001; Marriage et al., 2009; Murphy et al., 2011). However, to date few studies have used the ADOS and ADI-R for adults (Brugha et al., 2009a; Ecker et al., 2010).

Recognition and assessment of mental health problems in adults with intellectual disability and ASD

There is evidence that the prevalence and presentation of mental health problems in adults with intellectual disability and/or ASD is atypical compared with the general population (Einfeld & Aman, 1995; Hutton et al., 2008). This is thought to be due to complex relationships between a number of biological, psychological and social factors (Cooper & Simpson, 2006; Ghaziuddin, 2005; La Malfa et al., 2007). However, little is known about the aetiology and prognosis of mental health problems in these groups (Ruedrich, 2010). As such carrying out an assessment and making a valid and reliable diagnosis are considerable challenges (Kannabiran & McCarthy, 2009; Reiss et al., 1982). Nonetheless there have been significant advances in the classification and recognition of comorbid psychiatric disorders and multiple diagnoses are becoming more common (Gillberg, 2011; Rush, 2004).

As neurodevelopmental conditions with implications for functioning and adaptive skills, there are a number of characteristics common among people with intellectual disability and those with ASD that support the hypothesis that either group is at an increased risk of developing mental health problems (see Text box 2.1).

Text box 2.1: Bio-psycho-social-environmental risk factors for mental health problems that are common among individuals with intellectual disability and/or ASD

- Abnormal brain physiology and neurobiology
- Lower self-esteem, bullying and stigma
- Lack of protective factors – employment/occupation, social support
- Living in a restrictive environment
- Lack of control and independence
- Less well developed coping skills
- Lack of ability to understand and come to terms with stressors (e.g. bereavement or trauma)
- Deprivation/poverty

These include overlaps and similarities in symptoms between disorders (Helverschou et al., 2011). In addition there are a lack of: a consensus on what constitutes a mental health problem for these groups; standardised assessment and diagnostic tools; and specialists with expertise in assessing and diagnosing mental health problems (Einfeld & Aman, 1995; Mohiuddin et al., 2011; Sturmey, 1999).

Diagnosing mental health problems is hardest when an individual is unable to communicate. However even seemingly high functioning adults with intellectual disability and/or ASD may not be able to understand and express their emotions. These people can find it difficult to interpret and answer questions about their mental health (Leyfer et al., 2006; Kannabiran & McCarthy, 2009; Macneil et al., 2009).

Mental health problems in people with intellectual disability

In the past it was thought that people with intellectual disability did not suffer from mental health problems (Harris, 2006). If individuals displayed behavioural symptoms of psychiatric disorder it was assumed that these were features of intellectual disability itself (Einfeld & Aman, 1995; O'Brien, 2003). It has now been shown that people with intellectual disability can experience a range of mental health problems many of which are treatable (Raghaven, 2007). In fact, many mental health problems are more prevalent among those with intellectual disability than they are in the general population (Cooper et al., 2007; Deb et al., 2001b; WHO, 1992).

Experts describe a *pathoplastic effect* of intellectual disability on the symptoms of mental health problems (Cooper & Simpson, 2006; WHO, 1996). As severity of intellectual disability increases this effect becomes greater resulting in a more atypical presentation and making it harder to make an accurate assessment/diagnosis (Einfeld & Aman, 1995). Examples of

pathoplasticity and characteristics of intellectual disability that complicate the diagnostic process are shown in Text box 2.2 (see Cooper & Simpson, 2006; Einfeld & Aman, 1995; Sturmey, 1999).

Text box 2.2: Proposed effects of developmental level on mental health problems

- Ability to experience and understand complex and abstract concepts (e.g. guilt)
- Lower 'baseline' skills and functioning making it difficult to identify and quantify whether there has been a loss or decrease
- Different sleeping and eating patterns compared with adults in the general population
- Increased likelihood of presenting with symptoms less often seen in the general population (e.g. irritability or loss of communication skills)
- Different forms of symptoms (e.g. unusual delusions compared with those usually found in the general population)

There remains debate about what constitutes psychopathology in people with intellectual disability. Einfeld & Aman (1995) categorised the most prominent approaches as follows:

Educational	Challenging behaviours arise as a reaction to environmental stressors. As such changing a person's environment or helping them to adapt should reduce their problem behaviour.
Behavioural	Focuses on learnt maladaptive behaviours with identifiable antecedents and consequences.
Psychiatric	Behaviours indicate the presence of a treatable mental disorder.

Three arguments within the psychiatric model are proposed (Einfeld & Aman, 1995):

1) People with intellectual disability experience the same range of psychiatric disorders in the same way as the general population.

2) As above but a distinction is made between psychiatric disorder and behavioural problems that are 'non-psychiatric'.

3) Some psychiatric disorders are the same as in the general population but certain behaviours and problems are more common in people with intellectual disability and need new ways of categorisation and labelling.

The nature of the relationship between problem behaviours and psychiatric disorder are still disputed but there is evidence to support the theory that they are linked (Dudley et al., 1999). It has long been known that challenging behaviour is common among people with intellectual disability (Holden & Gitlesen, 2003). One view is that challenging behaviour is a behavioural equivalent of psychiatric symptoms in people with intellectual disability; therefore challenging behaviour may be an important indicator of the presence of psychiatric disorder (Beasley, 2000). There is some evidence to support this but studies have varied widely in approach, size and validity (Hemmings et al., 2006; Holden & Gitlesen, 2003; Jenkins et al., 1998; Kishore et al., 2005; Moss et al., 2000; Rojahn et al., 2004). It has been found that treating previously undiagnosed psychiatric disorders can lead to a reduction in the severity challenging behaviour (Tsiouris et al., 2003a).

Other studies have found mixed results depending on specific diagnoses and behaviours (Hemmings et al., 2008a) while others have found no association between psychiatric disorder and challenging behaviour (Tsiouris et al., 2003b). One study concluded that although mental health problems and challenging behaviour co-exist this does not mean they are related, causally or otherwise (Jenkins et al., 1998). Nonetheless, the presence of challenging behaviour in adults with intellectual disability increases the difficulty of accurately assessing their mental health.

Mental health problems in people with ASD

Research on the co-occurrence of mental health problems and ASD is at a very early stage (Kim et al., 2000; Medical Research Council, 2001). As with intellectual disability, it was previously thought that people with ASD did not suffer from additional mental health problems (Ghaziuddin, 2005). There was an initial reluctance to give individuals multiple diagnoses (particularly if they also had intellectual disability) and unease about applying notions of psychiatric disorder as described in the general population to those with ASD (Gadow et al., 2008).

Many of the issues described above also apply to people with ASD including diagnostic overshadowing and pathoplasticity (Helverschou et al., 2011; Barneveld et al., 2011). The Medical Research Council (2001) identified additional difficulties when assessing individuals with ASD: literal interpretation of questions, concrete thinking, and intense and unusual interests/preoccupations that can be confused with obsessions, compulsions and delusions.

Common features of ASD that overlap with indicators of mental health problems include self-injurious behaviour, aggression, unusual sensory responses, food fads, phobias, laughing or crying for no apparent reason and talking to oneself (Sverd, 2003). Identifying the onset and precise nature of these behaviours can help to identify whether they indicate the development of a mental health problem. This should be a key feature of any diagnostic assessment.

Little is known about the impact on mental health assessment when intellectual disability and ASD co-occur as there has been a lack of research on this specific topic (Bradley & Bolton, 2006; Underwood et al., 2010). There is some evidence that the estimated prevalence of mental health problems among adults with intellectual disability and ASD becomes lower when more stringent diagnostic criteria are applied compared with clinical assessment (Melville et al., 2008).

Diagnostic criteria for mental health problems

Using standard ICD and DSM criteria for adults with intellectual disability or ASD can be challenging for the reasons described above (Hassiotis et al., 2009a). Aside from practical issues, there have long been concerns that these systems are not applicable to individuals with intellectual disability, particularly those with moderate and severe forms (Einfeld & Aman, 1995; Perez-Achiaga et al., 2009; Rush, 2004).

As a result of this, two sets of criteria specifically for individuals with intellectual disability were developed: the *Diagnostic Criteria for adults with Learning Disability* and *Diagnostic Manual for Intellectual Disability*; based on ICD-10 and DSM-IV respectively (DC-LD; Royal College of Psychiatrists, 2001a & DMID; Fletcher et al., 2007). Individuals with low-functioning ASD are covered by the criteria in DC-LD and DMID but there is no evidence on their utility for this group. There are currently no specific diagnostic criteria or guidelines for assessing mental health problems in adults with ASD.

Despite the development of specific manuals for intellectual disability, most research and clinical practice on the mental health of adults with intellectual disability or ASD relies on the original DSM and ICD criteria (Ruedrich, 2010). This allows for standardised classification across different types of services and between different disciplines. Using generic criteria means that clinicians may be able to more easily assess eligibility for services, implement appropriate intervention, adhere to statutory guidelines and justify decisions on an individual's care.

Mental health assessment tools for people with intellectual disability

Structured and semi-structured interview tools developed to aid the diagnosis of mental health problems in adults with intellectual disability include the Diagnostic Assessment for the

Severely Handicapped-II (DASH-II; Matson, 1995); Present Psychiatric State for Adults with Learning Disability (PPS-LD; Cooper, 1997); Psychiatric Assessment Schedule for Adults with Developmental Disorders (PAS-ADD; Prosser et al., 1998); Psychopathology Instrument for Mental Retarded Adults (PIMRA; Matson et al., 1984) and Reiss Screen (Reiss, 1988).

There are also scales that assess mental health using a checklist of symptoms. Some provide a total score and subscales for specific diagnoses such as the PAS-ADD checklist (Moss et al., 1998) and Developmental Behaviour Checklist (Mohr et al., 2005). Others are condition specific; such as the Glasgow Depression Scale for people with intellectual disability (Cuthill et al., 2003).

Mohr & Costello (2007) carried out an updated review of tools that were reported to have potential for assessing the mental health of adults with intellectual disability (Aman, 1991). Comparison between the measures was limited due to the wide range of methods employed by studies and in their sample sizes. There was evidence on criterion and/or concurrent validity for the DASH, DBC, PAS-ADD, PIMRA and Reiss Screen. The authors considered that the internal consistency of these tools was adequate but found large variations in reports of test re-test and inter-rater reliability between different studies on the same instruments (Mohr & Costello, 2007).

Unwin & Deb (2008) reviewed the evidence on mental health and behavioural assessment scales. Only one purely psychiatric scale was identified (the PAS-ADD) described as a diagnostic or screening tool. Other scales – the DASH, Reiss Screen and PIMRA – were classified as *"Combined behaviour and psychiatric illness scales"*. The review stressed the difficulties in interpreting the results when using these scales since they include both behavioural and mental health symptoms without distinguishing between them.

Mental health assessment tools for people with ASD

A review of psychopathology assessment tools identified six instruments developed specifically for people with ASD (Underwood et al., 2011). There was limited evidence on the effectiveness of these tools and none were widely used in research or clinical practice. Two measures that were designed for adults had only been tested on those with severe and profound intellectual disability. The authors concluded that:

"People with ASD do not form a homogenous group for whom one tool will be applicable. Instruments need to take into account critical variables such as age, developmental level, communication skills and intellectual functioning. The standardized assessment of psychopathology in adults and children with ASD is a work in progress as tools need to be further developed and tested. There appears to be a particular lack of tools developed specifically for adults with higher functioning ASD. Existing and future tools must be developed to standards such as those set out by the American Psychiatric Association (1999). It is important that the psychometric properties and results of tests carried out on these instruments are comprehensively reported." (pp. 292)

The review recommended the use of tools developed for people with intellectual disability although it was acknowledged that there was also a lack of evidence on their effectiveness for people with ASD (Underwood et al., 2011; see Appendix I for the full text of this review on the assessment of psychopathology in ASD).

The standardised assessment and monitoring of individuals' mental health and behaviour is strongly recommended by guidelines on intervention and service provision for people with intellectual disability (Deb & Unwin, 2006). A range of tools have been developed to help services monitor the outcomes of people receiving mental health care. These include the HoNOS-LD (Roy et al., 2002), the Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM; Evans et al., 2000) and a number of quality of life instruments

(Townsend-White et al., 2011). Measures used in studies on outcome for adults with intellectual disability also include Global Assessment of Functioning (GAF; APA, 1987) and Threshold Assessment Grid (TAG; Slade et al., 2000) (Hall et al., 2006).

However, none of these instruments focus on mental health symptoms or measure overall levels of psychopathology. A lack of well-evaluated measures is a widely recognised problem for clinicians and researchers (Kellett et al., 2004; Underwood et al., 2011). Just five tools were identified in a review of the literature on mental health scales for adults with intellectual disability.

Two measures have been developed by Matson et al.: the Assessment of Dual Diagnosis for those with mild/moderate intellectual disability (Matson & Bamburg, 1998) and the Diagnostic Assessment for the Severely Handicapped-II (DASH-II) for those with severe intellectual disability (Matson, 1995). Although the DASH-II has been used in several studies of those with and without ASD (see Table 4.1) there is no evidence for its use with adults who have mild/moderate intellectual disability.

It has been suggested that the Brief Symptom Inventory (BSI) and Symptom Checklist 90-Revised (SCL-90-R) can be used with individuals with mild intellectual disability (Kellett et al., 2004). However, both rely on self-reported symptoms and are therefore not suitable for those with moderate or severe intellectual disability. Nor were they specifically designed to pick up behaviours and symptoms that may be more common among people with intellectual disability than the general population.

The Developmental Behaviour Checklist for Adults (DBC-A) was designed to assess behavioural and emotional disturbance among people with intellectual disability (Mohr et al., 2004). An informant rates 109 items according to whether specific behaviours occurred: never, sometimes or often over the last six months. A total score and six subscale scores can

be calculated. The scale has validated cut-off points for 'psychiatric caseness' with varying degrees of specificity and sensitivity when compared with clinical psychiatric diagnosis.

Among the tools reviewed by Mohr & Costello (2007) the DBC-A had the highest internal consistency, specificity and sensitivity. Many tools such as the PAS-ADD checklist and DASH-II were designed to be diagnostic assessments and the use of their total scores is not appropriate.

Assessment of problem behaviour

A review of behavioural assessment scales identified just three tools that had sufficient evidence on their development or psychometric properties (Unwin & Deb, 2008). These were Aberrant Behaviour Checklist (ABC), AAMR Adaptive Behaviour Scale and Behaviour Problems Inventory (BPI).

The ABC is a well-known tool designed especially for people with intellectual disability (Aman et al., 1985). The 58 items are scored from zero (no problem) to three (severe problem) by an informant on the basis of the person's behaviour over the previous four weeks. The scale is widely used and has good reported psychometric properties (Rojahn et al., 2011; Unwin & Deb, 2008).

The AAMR's Adaptive Behaviour Scale (1992) features a section on 'social maladaptation' that has been found to have limited reliability (Unwin & Deb, 2008). The 52-item BPI-01 measures the frequency and severity of self-injurious, stereotyped and aggressive/destructive behaviours (Rojahn et al., 2001). It has been found to have good internal consistency, reliability and clinical criterion validity (Rojahn et al., 2010; Unwin & Deb, 2008).

Studies comparing adults who have intellectual disability with and without ASD have used the ABC, BPI-01 and the Disability Assessment Schedule (Rojahn et al., 2010; Totsika et al., 2010; Tsakanikos et al., 2011).

Conclusion on the recognition and assessment of intellectual disability, ASD and comorbid mental health problems

There is good evidence that the challenges of making a diagnosis result in the under recognition of intellectual disability, ASD and comorbid mental health problems in adults. This can lead to the under treatment of mental health problems in adults with intellectual disability and ASD (Xenitidis et al., 2007). Defining and recognising the characteristics of groups within intellectual disability/ASD populations is of great importance (Schroeder & Reese, 2007). However, it cannot be done with sufficient reliability and validity without effective assessment tools.

The assessment of mental health problems in adults with intellectual disability and/or ASD is less straightforward than for the rest of the population. Some tools used in the general populations are clearly not suitable for adults with intellectual disability or ASD because they are unable to understand or answer the questions. Others assume a 'normal pre-morbid' level of functioning (Royal College of Psychiatrists, 2009b). Given these difficulties few reviews or guidelines recommend any one particular instrument and the gold standard is cited as: "*clinical diagnosis by a specialist, provided comprehensive assessments and measurements have been used*" (Cooper et al., 2007, pp.32).

Further research is needed to determine the accuracy of clinical diagnoses of ASD and comorbid mental health problems in adults with intellectual disability and what effect this may have on service provision and outcome (Underwood et al., 2012). Currently the best way to explore the mental health of adults with intellectual disability and ASD would appear to be using those tools available for screening and diagnosis in adults with intellectual disability.

Chapter 3: Prevalence of intellectual disability, ASD and comorbid psychiatric disorder

Epidemiological studies of mental health problems have been carried out since the 19th century (Prince et al., 2003). Research on the prevalence and patterns of disorders is used to explore the causes of mental health problems, identify risk factors, develop services and interventions, and predict outcome (Prince et al., 2003). A 'gold standard' observational epidemiological study would be prospective, longitudinal and comparative (e.g. a cohort study). Although, prevalence studies are more likely to be cross-sectional (Ford, 2003). These types of study are lacking in the fields of intellectual disability and ASD research with very few that were truly designed to study the epidemiology of these conditions particularly with respect to comorbid mental health problems (Hove & Havik, 2010; Smiley, 2005; Sverd, 2003).

Estimated rates of a condition can differ greatly over time, between populations and between studies depending on a number of factors. As well as changes in the actual prevalence rate, these include the definition of the condition being studied, the methods used to sample the population and assess them, sample size, ease of recognition and the rate of identification in the general population.

Prevalence of intellectual disability

Intellectual disability is often described as the most common developmental disorder and causes a great deal of burden worldwide (WHO, 2001). Diagnostic criteria include the stipulation that individuals with intellectual disability have an IQ lower than 70 (APA, 1994; WHO, 1992). This is based on the principal that level of 'intelligence' as measured by IQ is normally distributed among the population; with an average score of 100 and one standard deviation of 15 points. Given this it would be expected that around 2.5% of the population

have intellectual disability (i.e. an IQ lower than two standard deviations from the population mean of 100). However, this is an overestimate of prevalence since mortality rates are much higher among those with very low IQ (Bhate & Wilkinson, 2006; Emerson, 2009).

Estimates of intellectual disability prevalence worldwide range from 1 to 3% (Harris, 2006). A recent meta-analysis of 52 population-based studies estimated a rate of 10.37 per 1000 people (Maulik et al., 2011). The number of people with intellectual disability is increasing across the lifespan (Emerson & Hatton, 2008). As the general population ages, the number of adults and older adults with intellectual disability is increasing particularly among 40-59 year olds (Department of Health, 2001b).

Characteristics of individuals with intellectual disability

The proportion of individuals with each severity of intellectual disability is estimated to be 85% mild, 10% moderate and 5% severe/profound (Bhate & Wilkinson, 2006). The rate of mild intellectual disability is said to be higher among males than females but this is not found consistently across studies (Harris, 2006; Maulik et al., 2011). There is evidence that rates of mild-moderate intellectual disability are higher in deprived and urban areas (Department of Health, 2001b; Emerson, 2010). Prevalence of intellectual disability in the UK appears to be higher among young people from South Asian communities (Department of Health, 2001b; Emerson & Hatton, 2005a).

Prevalence of ASD

The most commonly quoted prevalence rate of ASD among the general population is 1%. However, estimates actually range from between four and 157 cases per 10 000 (Baron-Cohen et al., 2009). The exact number of people with ASD in the UK is currently unknown (Department of Health, 2006; National Audit Office, 2009b).

There is great debate about whether we are experiencing an 'autism epidemic' (Charman, 2011). Although it does appear that rates of ASD are increasing over time (from 0.04% in 1978) the reasons for this are complex and manifold (Baron-Cohen et al., 2009). Most older studies measured the prevalence of autism rather than the wider spectrum of disorders that are included in more recent estimates. In addition, regardless of whether or not the actual rate of ASD has increased the number of individuals identified and receiving a diagnosis has. This is largely because of improvements in awareness and recognition, greater provision of services and wider diagnostic criteria (Barbaresi et al., 2008; Medical Research Council, 2001).

The majority of early studies focussed on children but there is increasing interest in measuring prevalence among adults not least to confirm or refute whether ASD is becoming more common. If theories of an increasing rate of ASD are correct there should be a negative relationship between prevalence of ASD and age with much lower rates among older adults (Brugha et al., 2011). However, the few studies that have been carried out on adults found similar rates to studies on children (Baron-Cohen et al., 2009; Brugha et al., 2009b; Brugha et al., 2011).

There is evidence that measuring prevalence by identifying clinical or administrative cases leads to an underestimation of the number of people with ASD compared to systematic screening (Barbaresi et al., 2008; Baron-Cohen et al., 2009; Emerson & Baines, 2010). In a review by Fombonne (2003) relationships between prevalence estimates and methodological variations were marked. There was a negative correlation between sample size and prevalence, and a positive correlation between year of publication and prevalence. Only two studies accounted for the reliability of the screening measure they used.

Most prevalence studies use standardised ASD assessment measures. However, many (including population-based studies aiming to identify those without an existing diagnosis)

rely on reviews of case notes rather than direct assessment of participants. In children, this method appears to be associated with somewhat lower estimates of ASD prevalence (e.g. Barbaresi et al., 2008; Centers for Disease Control & Prevention, 2009). Limited data on whether rates of ASD are higher among adults with mental health problems are available from two studies. However, each had different results with one appearing to show an elevated rate (Nylander & Gillberg, 2001) but the other a lower rate (Chang et al., 2003).

There is consistent evidence that ASD is more prevalent among males than females with the ratio varying between 2.5:1 and 4.5:1 (Barbaresi et al., 2008; Carter et al., 2007; Centers for Disease Control & Prevention, 2009). The evidence for differing rates according to ethnicity is somewhat mixed. Some studies have found higher rates among white individuals and an under representation of people from black and ethnic minorities within ASD samples (Centers for Disease Control & Prevention, 2009; Mandell et al., 2008). However, it is likely that selection or referral biases and under diagnosis partially account for these differences (Begeer et al., 2008).

Adults with intellectual disability and ASD

Intellectual disability and ASD are known to commonly occur together (Matson & Shoemaker, 2009). As the diagnostic criteria for ASD has widened the proportion of people with high-functioning ASD has increased and current estimates of the prevalence of intellectual disability among those with ASD are much lower than they were in the past (Bhaumik et al., 2010). On the other hand, improvements in recognition and assessment have lead to an increase in the proportion of people with intellectual disability who have a diagnosis of ASD.

Most of the literature indicates that at least 50% of people with ASD have intellectual disability with some estimates reaching 70% (Baird et al., 2006; La Malfa et al., 2004; Matson & Shoemaker, 2009). However lower rates have been found and are more likely in studies that include people with high-functioning ASD. For example a large US study found a rate of 41% (Centers for Disease Control & Prevention, 2009). In the hospital statistics included in Emerson & Baines's (2010) review 32.6% of adults with ASD also had a diagnosis of intellectual disability. In the review of the literature on prevalence of intellectual disability among children with ASD the author's derived estimated rate was 40-67%. A recent meta-analysis of studies on children found a rate of 76% in autism and 65% in ASD (NICE, 2011). The rate referred to most often is 55%; found by Baird et al (2006).

Rates of ASD in people with intellectual disability

As with studies on the prevalence of ASD in the general population there is great variation in the estimated rates of ASD among people with intellectual disability. As Table 3.1 shows the estimated prevalence of ASD among people with intellectual disability ranges from around 8% up to 40%. The only comprehensive population-based screening study found surprising low rates of ASD, particularly when stringent DSM-IV criteria were applied (Cooper et al., 2007). It is not clear why this might be, however the study used a broad-based measure of physical and mental health rather than a specific ASD assessment to screen for potential cases. This may have resulted in the under-identification of individuals with ASD.

Other studies tended to find rates of 20 to 40% and there was evidence that there was a high level of undiagnosed or unconfirmed ASD among adults with intellectual disability (Hare et al., 2003; La Malfa et al., 2004; Saemundsen et al., 2010).

Table 3.1: Recent studies reporting rates of co-occurring intellectual disability and ASD

	Method	Population	Diagnostic assessment	Prevalence estimate	Additional notes
de Bildt et al., 2005	Assessment of all children with ID in a geographical area.	825 children with ID in the Netherlands (aged 4-18)	Phase 1: PDD-MRS & ABC Phase 2: ADI-R, ADOS & DSM-IV-TR classification	ADI-R: 16.8% ADOS: 19.8% DSM-IV-TR: 16.7%	Rates were higher among those with moderate to severe ID compared with mild ID
Bryson et al., 2008	Further assessment of those identified by population-based study on prevalence of ID	171 adolescents with IQ≤ 75 in Canada (aged 14-20)	ADI-R	28.2% (95%CI: 21.2-35.2%)	No significant difference in rate of ASD between severe (32%) and mild ID (24%)
Cooper et al., 2007	Population-based screen of a geographical area	1023 adults with ID in the UK	Phase 1: C21st Health Check. Phase 2: clinical diagnosis by ID psychiatrist	7.5% (clinical diagnosis)	Rate fell to 2% when DSM-IV-TR diagnostic criteria were applied.
La Malfa et al., 2004	Assessment of residents in two institutions for people with ID	166 adults with ID in Italy.	Phase 1: PDD-MRS. Phase 2: clinical review using DSM-IV & ICD-10 criteria	39.2%	Prevalence of existing ASD diagnoses was 7.8%.
Morgan et al., 2002	Assessment of those in contact with ID services	571 adults with ID in the UK	Phase 1: PDD-MRS. Phase 2: clinical diagnosis by ID psychiatrist using ICD-10	30%	Severe ID prevalence = 57%, moderate=31%, mild=12%. Prevalence of ASD decreased with age.
Saemundsen et al., 2010	Assessment of adults with severe ID in one city	119 adults with severe ID in Iceland	Phase 1: The Bryson scale. Phase 2: CARS. Phase 3: ADI-R	21% (95% CI 14.7–29.2)	Prevalence of existing ASD diagnoses was 9%
Totsika et al., 2010	Assessment of participants in five studies on staffed group homes & a primary care service	819 adults with ID in the UK	Assessed as having the triad of impairments characteristic of ASD using the DAS-B	34.3%	Assessments were based on case note reviews
Hare et al., 2003	Identification of those with confirmed or suspected ASD	Estimated 1723 adult service users with ID in the UK	Clinical diagnosis reported by service providers	10.1%	Only 33% of identified cases had a confirmed diagnosis of ASD.
Bhaumik et al., 2010	Identification of individuals with an existing ASD diagnosis from a specialist psychiatric service for adults with ID	1145 adults with ID in the UK	Clinical diagnosis according to ICD-10 criteria	19%	No evidence that some clinicians diagnosed ASD more than others
Bouras et al., 2003	Assessment of referrals to a mental health service for adults with ID	752 adult mental health service users with ID	Clinical diagnosis by ID psychiatrists using ICD-10	19.5%	No significant change in proportion of service users with ASD over time (1983 to 2001)

ABC=Autism Behavior Checklist, CARS=Childhood Autism Rating Scale, DAS-B=Disability Assessment Schedule-Behaviour checklist, PDD-MRS=Pervasive Developmental Disorder in Mental Retardation Scale

Estimates of ASD among adults with intellectual disability using psychiatric or mental health services tended to fall at the lower end of the range, however both studies reporting this relied on routine clinical diagnoses (Bhaumik et al., 2010; Bouras et al., 2003).

Emerson & Baines (2010) carried out a systematic review of prevalence studies published since 2000. The five studies that met their inclusion criteria reported a wide range of results, the authors of the review estimated that the prevalence rate of ASD among adults with intellectual disability lies between 20 and 33%.

The accuracy of prevalence rates of ASD in people with intellectual disability are confounded by the level of cross-over between the two conditions and difficulties in assessment (Bhaumik et al., 1997). A recent study found that of 925 participants with intellectual disability and no clinical diagnosis of ASD, 20% were reported to have two or more ASD traits. They were more likely to be aged over 50 and have other mental health problems but less likely to have mild intellectual disability or behaviour problems (Bhaumik et al., 2010). Unfortunately these individuals were not further assessed to determine whether they had undiagnosed ASD.

Patterns of prevalence of co-occurring intellectual disability and ASD

There is a direct relationship between severity of intellectual disability and ASD; prevalence of ASD increases at each level of severity (Matson & Shoemaker, 2009). A number of studies have compared the characteristics of adults who have intellectual disability with and without ASD. This research has found that adults with intellectual disability and ASD tend to be younger, male and have more severe intellectual disability than those with intellectual disability alone (Lunsky et al., 2009; Melville et al., 2008; Morgan et al., 2003; Tsakanikos et al., 2006). There is evidence that the ratio of males to females with ASD is more even among individuals with intellectual disability and becomes more so as severity of intellectual

disability increases (Fombonne, 2003). Research has also found differences between individuals who have intellectual disability with and without ASD on social skills, language ability, adaptive behaviour (Wilkins & Matson, 2008).

Psychiatric disorder among adults with intellectual disability and ASD

As with research on the prevalence of intellectual disability and/or ASD, the methods used by studies on the prevalence of mental health problems in these groups vary a great deal (Varghese & Banerjee, 2011). In addition to different ways of diagnosing intellectual disability/ASD, there are many variations in the definition and assessment of mental health problems. Some studies focus on presence/absence of psychiatric disorder in general where as others focus on specific diagnoses such as psychotic disorder or depression.

Rates of psychopathology in people with intellectual disability

ICD-10 suggests that the prevalence of psychiatric disorder among people with intellectual disability is three to four times greater than in the general population (WHO, 1992). Estimated rates derived from research studies have ranged greatly from 10% up to 60%. A study by Deb et al (2001b) screened for psychiatric disorder among a randomly selected group of 101 adults with intellectual disability who lived in the community. The results were compared with estimates in the general population. The rates for any psychiatric disorder according to ICD-10 criteria were similar (14.4% for those with mild and moderate intellectual disability versus 16% for the general population). However, rates were significantly higher among those with mild/moderate intellectual disability for schizophrenia and phobia disorders. A larger study (N=1023) found similar results when using strictly applied ICD-10 criteria but a higher prevalence of 22.4% when relying on clinical diagnoses by intellectual disability psychiatrists. This rate increased to 40.9% when problem behaviours and ASD were included as types of psychopathology (Cooper et al., 2007).

In a Norwegian study of 593 adults with intellectual disability, 22% of participants had a history of psychiatric disorder (Hove & Havik, 2008). Applying the Psychopathology Checklists for Adults with Intellectual Disability, the study found that 35% met this measure's criteria for psychiatric disorder. A study that combined a register of adults with intellectual disability and one of people with mental health problems in Australia identified 4221 individuals with a dual diagnosis (Morgan et al., 2008). This represented 1.7% of the total sample; 31.7% of those with intellectual disability had a psychiatric disorder. The prevalence of schizophrenia among those with intellectual disability was 3.6% (compared with around 1% for the general population).

A review of research on the mental health of people with intellectual disabilities found 85 studies; those on prevalence were categorised into five types (Ruedrich, 2010). Rates of psychiatric disorder varied considerably from 10-37% (in population studies) and 15-35% (in institutional/community-based studies). Among individuals referred for psychiatric evaluation, the prevalence of psychiatric disorder ranged from 53% up to 90%. Rates reported in reviews of specific diagnoses were ADHD: 14-60%; anxiety: 2.8-35%; mood disorders: 9-20%; personality disorders: 1-22%; and psychotic disorder (1.3%-5.2%). The authors also found a number of studies that reviewed comorbidity in those with specific aetiology of intellectual disability.

Pattern of diagnoses among people with intellectual disability & psychiatric disorder

In a study of mental health services users with intellectual disability in Australia the most common psychiatric diagnosis was schizophrenia followed by mood disorders (including bipolar disorder), personality, anxiety and dementia (Pridding & Tomasoni, 2006). A very similar pattern was found in the UK where a third of those with a psychiatric disorder had schizophrenia (Bouras et al., 2003). In contrast, a study in the United States found that most

mental health service users with intellectual disability had diagnoses of affective disorders (Hackerman et al., 2006). Psychotic disorders accounted for only 15% of diagnoses.

Rates of psychopathology in people with ASD

The risk of additional psychopathology is thought to be higher among people with ASD than the general population (Kannabiran & McCarthy, 2009; Kring et al., 2008). This is perhaps to be expected since at least 50% of people with ASD also have intellectual disability which is a known risk factor for mental health problems. While higher rates of psychotic disorder are seen among people with intellectual disability, the disorders that appear to be more prevalent in people with ASD are depression/mood disorders and anxiety (*Davis et al., 2008*; Ghaziuddin et al., 2002; Macneil et al., 2009; Mazefsky et al., 2011; Munesue et al., 2008; Steensel et al., 2011). This could be due to the difficulties in diagnosing psychosis in people with ASD or the type of studies carried out, particularly as most are on children in whom psychotic disorders are rare (Bakken et al., 2007; Mattila et al., 2010).

As always, estimated rates of psychiatric disorder among people with ASD vary according to study population and methods which can make estimating an overall level of prevalence very difficult (Kanne et al., 2009a; Macneil et al., 2009). Many early estimates were based on case studies and small sample sizes and there has been a lack of epidemiological studies in this area (Howlin, 2000; Lainhart & Folstein, 1994). Many studies do not include a comparison group making it difficult to ascertain how the rates found differ between those with and without ASD (White et al., 2009). The NICE guideline on ASD in children was only able to produce evidence statements on the prevalence of comorbid anxiety (27%), depression (9%) and OCD (8%) because there were no studies of sufficient quality on other psychiatric diagnoses (NICE, 2011). However, it is thought that people with ASD experience a range of other disorders (Sverd, 2003).

Table 3.2 shows the range of rates reported by studies reviewed for the thesis. Estimated prevalence in the general population is also shown as a comparison. Although there does appear to be an increase in prevalence of most disorders among those with intellectual disability and/or ASD, the estimates vary a great deal.

Table 3.2: Variation in estimates of prevalence of mental health problems

Psychiatric disorder	General Population[1]	People with ID	People with ASD	People with ID & ASD
Any diagnosis	16%	10-59%	9-89%	5-53%
Anxiety disorder	6.9%	2-41%	7-84%,	3-77%
Bipolar disorder	1%	13%	9-39%	2-77%
Depression	2.3%	10-15%	5- 50%	2- 64%
OCD	1.1%	3-12%	1- 25%	0-13%
Personality disorder	4.4%	8%		
Psychotic disorder	0.4%	1-18%	0-53%,	1-30%

(Bakken et al., 2010; *Bradley & Bolton, 2006*; Ghaziuddin et al., 1998; Green et al., 2000; Gjevik et al., 2010; Helverschou & Martinsen, 2011; Hill & Furniss, 2006; Hofvander et al., 2009; Howlin, 2000; Hutton et al., 2008; Lai et al., 2011; Leyfer et al., 2006; Mattila et al., 2010; Mazefsky et al., 2011; Mehtar & Mukaddes, 2011; Padgett et al., 2010; Patel et al., 1993; Reid et al., 2011; Strydom et al., 2010; Tantam, 2000; Tsiouris et al., 2011; Totsika et al., 2010; Varghese & Banerjee, 2011)

Most of the studies reviewed in Table 3.2 were on children. Recent research is providing an overall picture of psychopathology among adults with ASD. For example a study of 122 adults with ASD in Sweden found that 53% had a mood disorder, 50% an anxiety disorder, 24% had OCD and 12% a psychotic disorder (Hofvander et al., 2009). In a study that followed-up 135 children with ASD into adulthood, 16% developed new psychiatric disorders mainly anxiety and affective (Hutton et al., 2008). Padgett et al (2010) looked at non-affective psychosis in ASD and although the studies identified were too heterogeneous to meta-analyse the authors suggested that a rate of 7.8% was the most reliable. A recent review found that among adults with ASD, anxiety disorders were most common (5-35% for generalized anxiety, 10-64% for phobias and 1-37% for OCD), followed by affective disorders (0-50%) and schizophrenia (0-6%) (Skokauskas & Gallagher, 2010). It has been suggested that the

[1] Sourced from the Adult Psychiatric Morbidity in England survey 2007 (McManus et al., 2009)

prevalence of anxiety is lower among individuals with low-functioning ASD than it is among those without intellectual disability (Helverschou & Martinsen, 2011). There is some evidence that the risk of mental health problems (including ADHD, anxiety and depression) increases as the number of ASD traits an individual has increases (Lundström et al., 2011).

Attention deficit hyperactivity disorder (ADHD)

ASD is an exclusionary diagnosis for ADHD in ICD-10 and DSM-IV because people with ASD often exhibit symptoms of hyperactivity (Funabiki et al., 2011). However, in practice, it is generally recognised that ASD and ADHD co-occur (Bradley & Isaacs, 2006; Brereton et al., 2006; Department of Health, 2010b). A meta-analysis carried out for the NICE guideline on ASD in children estimated that 45% of those with ASD also have ADHD (NICE, 2011).

Rates of psychopathology in adults with intellectual disability & ASD

It appears that individuals with ASD are more likely to experience mental health problems than the general population but it is not clear whether this is associated with the fact that a significant proportion of people with ASD have intellectual disability. To date few studies have focused specifically on mental health problems in individuals with both intellectual disability and ASD (Bakken et al., 2010).

Many studies on psychopathology in ASD focussed on high-functioning ASD and few differentiate between those with and without intellectual disability (Hill & Furniss, 2006). Many found that higher rates or symptoms of psychiatric disorder were associated with lower cognitive and functional impairment (Leyfer et al., 2006; Steensel et al., 2011). Others have found a relationship between high-functioning ASD and increased psychopathology (Mayes et al., 2011a; Vickerstaff et al., 2006).

Most of the early studies that compared those with intellectual disability and ASD to those with intellectual disability alone were on children and adolescents (Matson & Shoemaker, 2009). Research appeared to show an increased risk among those with both conditions (Bradley et al., 2004; Bradley & Bolton, 2006; Brereton et al., 2006). Participants with ASD appeared to have particularly high rates of anxiety, depression and manic disorders compared to those without ASD. There have been few studies on the mental health of adults with intellectual disability and ASD (Underwood et al., 2010). Table 3.3 details studies that have measured the prevalence of psychiatric disorder among adults who have intellectual disability with and without ASD.

In one of the first studies, Morgan et al. (2003) found that adults with intellectual disability and ASD had significantly increased lifetime prevalence of depression and bipolar disorder; but there was no difference in the rate of schizophrenia compared with those who had intellectual disability alone. Bakken et al. (2010) found higher rates of anxiety, depression and psychotic disorders in those with ASD compared to those without ASD. A study of psychiatric in- and out-patients in Canada found that most of those with intellectual disability and ASD had a psychiatric disorder but they were less likely to have a psychotic disorder than those without ASD or those with neither intellectual disability nor ASD (Lunsky et al., 2009).

By contrast, a study in London found lower rates of psychiatric disorder in adults with ASD and intellectual disability attending a specialist mental health service than in those without ASD (Tsakanikos et al., 2006). A separate analysis of the data from this sample found that most of those with ASD did not have a psychiatric disorder although the rate of comorbidity appeared to be increasing over time (Tsakanikos et al., 2007).

Table 3.3: Studies on the prevalence of psychiatric disorder in people who have intellectual disability with and without ASD

Study	Population	N ASD+ID	N ID	Measure of psychopathology	Results for ASD + ID vs. ID
Bakken et al., 2010	Adults & adolescents. ASD assessed by clinical diagnosis using ICD-10 criteria	62	132	PAC	Any psychiatric disorder: 53% vs.17%, psychosis: 25% vs. 9%, depression: 37% vs. 15%, anxiety: 34% vs. 9%, OCD: 13% vs. 3%, all $p<0.05$
Melville et al., 2008	Adults. Matched on gender, age, severity of ID. ASD identified using C21st Health Check and assessed by clinical diagnosis.	77	154	Clinical diagnosis (DC-LD, ICD-10 & DSM criteria)	Mental ill-health excluding problem behaviours: 21% vs. 23%, including problem behaviours: 48% vs. 40%, both $p>0.05$
Morgan et al., 2003	Adults. ASD identified using PDD-MRS and assessed by clinical diagnosis using ICD-10	164	400	Clinical diagnosis based on ICD-10	41% had a psychiatric disorder. Rates were higher for depression (20% vs. 3%) & bipolar (11% vs. 2%), both $p<0.05$, no difference in prevalence of schizophrenia.
Totsika et al., 2010	Adults (aged 50+). Subsample matched on functioning. ASD assessed using DAS-B	87	195	PIMRA & PAS-ADD	Psychiatric caseness in unmatched sample: 32% vs.23%, $p=0.09$, psychiatric caseness in matched sample: 37%(N=65) vs. 27% (N=65), $p=0.11$
Lunsky et al., 2009	Adult mental health patients. Matched on gender & inpatient/outpatient status. ASD assessed by clinical diagnosis	23	23	Clinical diagnosis using ICD-9	Lower rate of psychosis:26% vs. 78%, $p<.01$). No significant difference on other disorders. Lower rate of psychosis compared with 23 mental health patients with no ASD or ID:83%,$p<.01$
Tsakanikos et al., 2006.	Adult mental health patients. ASD assessed by clinical diagnosis using ICD-10 criteria	147	605	Clinical diagnosis ICD-10,PASADD	Any psychiatric disorder: 36% vs. 55%,$p <.01$. PD: 3% vs. 9%, $p<.01$. $p>.05$ for anxiety: 4% vs. 8%, depression: 6% vs. 9% & psychosis: 16% vs. 19%.
Charlot et al., 2008	Adult inpatients with depression. Matched on age, gender & ID severity. ASD assessed by clinical diagnosis using DSM-IV-TR criteria	13	40	MASS	Prevalence of comorbid anxiety: 62% vs. 38%

ASD-CA=ASD-Comorbidity for Adults scale, DASH-II=Diagnostic Assessment for the Severely Handicapped-II, MASS=Mood & Anxiety Semi-Structured Interview for Patients with ID, PAS-ADD= Psychiatric Assessment Schedule for Adults with Developmental Disorders, PDD-MRS=Pervasive Developmental Disorder in Mental Retardation Scale, PIMRA= Psychopathology Instrument for Mental Retarded Adults, SAPPA= Schedule for the Assessment of Psychiatric Problems Associated with Autism (and Other Developmental Disorders)

More recently, a population study in the UK found some differences in behavioural problems but not in psychiatric disorders between adults who had intellectual disability with and without ASD (Melville et al., 2008). Totsika et al., (2010) explored the mental health of older adults with intellectual disability. No differences were found in the rates of psychiatric disorder, problem behaviours or quality of life between those with and without ASD.

In the study by Morgan et al. (2008) of psychopathology in adults with intellectual disability, ASD was significantly more prevalent among those with a psychiatric disorder. A study of factors associated with mental health problems in adults with intellectual disability included a small number of people with ASD (N=25, 4.4% of the sample) (Hove & Havik, 2010). ASD was associated with higher levels of psychotic disorder, anxiety, OCD and problem behaviour. However, after controlling for factors included age, gender and presence of ASD, severity of intellectual disability was the only variable significantly associated with psychopathology.

In summary, the results of these studies were extremely variable. There are two key issues to bear in mind when evaluating the evidence on whether there are differences in the prevalence of psychopathology between those who have intellectual disability with and without ASD:

- The accuracy of participants' allocation to the ASD and no ASD groups
- Whether the study carried out a comprehensive diagnostic assessment of psychiatric disorder or accepted that exceeding the threshold on a checklist or rating scale was sufficient for a participant to be given a diagnosis.

Studies that do not carry out standardised ASD assessments may be less likely to find differences between those with and without a diagnosis since there could be many individuals with ASD among those in the 'no ASD' group. This could be an issue for the Melville et al.

study (2008) in which, as discussed earlier, a particularly low rate of ASD was found (see Cooper et al., 2007). Conversely, using cut-off scores on an assessment tool as the sole determinant of whether a participant has a psychiatric disorder could lead to an overestimation of prevalence among those with ASD. Individuals with ASD are likely to present with a range of behaviours that will increase their score on a rating scale of psychopathology. In a clinical diagnostic assessment it would be possible to ascertain more accurately whether these symptoms are due to their ASD or an additional mental health problem (Bradley et al., In press).

A further issue is the lack of studies on non-clinical populations among which there may be high levels of referral bias. As such, of the studies described in Table 3.3, only Morgan et al. (2003) can be said to be of a high enough standard to provide good quality evidence on differences in the prevalence of psychiatric disorder among adults who have intellectual disability with and without ASD. However, this study did not attempt to match those with and without ASD or take any other factors into account during the analysis of the data even though the authors acknowledged there was a high rate of severe intellectual disability among those with ASD.

Patterns of prevalence and characteristics associated with psychiatric disorder in adults with intellectual disability & ASD

There is a lack of consensus among studies on the prevalence of mental health problems in people with intellectual disability on whether there are differences according to age, gender, living situation or severity of intellectual disability (Driessen et al., 1997; Hove & Havik, 2010). Furthermore, when differences have been found it is not clear whether these could be due to measurement or selection biases, particularly if the studies are based on clinic populations (Hove & Havik, 2010).

Many studies on the patterns mental health problems in ASD are on children and it is debateable whether differences found with respect to age, gender, ethnicity or IQ are likely to be sustained in to adult life. Research on gender differences is lacking due to the lower prevalence of ASD in females. Many studies include mainly or only male participants so much of the evidence available on the relationships between ASD and mental health problems may only really be relevant to high-functioning male children.

There is some evidence for higher rates of psychiatric disorder among those with mild intellectual disability. For example Morgan et al. (2008) found that compared to those with intellectual disability alone, participants with additional mental health problems were more likely to have mild intellectual disability. Morgan et al. (2003) found that prevalence of psychiatric disorder in those with ASD was 65% among those with mild intellectual disability compared with 35% among those with moderate and 40% for severe intellectual disability. Studies have found a positive correlation between IQ and rates of disorder, particularly depression and anxiety (Mayes et al., 2011b). Others have found no such association (Munesue et al., 2008).

Since the rate of ASD is known to increase with intellectual disability severity the interactional effect of these two factors on psychopathology is unclear. It is often found that once severity of intellectual disability or adaptive functioning are accounted for, differences in the prevalence of psychiatric disorder between those with and without ASD are less pronounced or no longer significant (Hove & Havik, 2010; Totsika et al., 2010).

Factors that appear to predict increased psychopathology among adults with intellectual disability and ASD include social problems, fewer daily living skills, low social skills, negative life events, health problems and a family history of mental health problems

(Ghaziuddin et al., 1995; Ghaziuddin & Greden, 1998; Horovitz et al., 2011; Hove & Havik, 2010; Matson et al., 2009; Piven & Palmer, 1999). There is evidence that multiple risk factors in an individual are related to greater severity of psychiatric symptoms and that certain factors are more clearly associated with specific disorders (e.g. complications in pregnancy and phobia; Gadow et al., 2008). It is also thought that there are differences in rates of mental health problems according to aetiology of intellectual disability (Ruedrich, 2010). There is a consistent finding that individuals with intellectual disability and ASD who have mental health problems are often diagnosed with more than one psychiatric disorder (Bakken et al., 2010; Ghaziuddin et al., 2002; Melville et al., 2008).

Conclusion on the prevalence of intellectual disability, ASD and comorbid mental health problems

The exact number of adults with intellectual disability, ASD and comorbid mental health problems remains unclear. There are wide ranges in the estimated rates of these conditions. Although there appears to be consistent evidence that rates of ASD are getting higher over time, the cause of this apparent increase is not yet established. It is most likely the result of a combination of factors including wider diagnostic criteria and better recognition. Improving the accuracy of estimates of the prevalence and incidence of intellectual disability, ASD and mental health problems should be an important priority for researchers and policy makers. More high-quality studies are needed to establish whether adults with intellectual disability and ASD are at increased risk of mental health problems compared to those without ASD.

Chapter 4: Mental health, behaviour and social functioning of adults with intellectual disability and ASD

Previous chapters revealed the extent of comorbidity among adults with intellectual disability and ASD and the effect this has on assessing and diagnosing individuals' problems. This chapter explores the impact this complexity has on people's lives. Intellectual disability, ASD and mental health problems are often associated with unemployment, lack of independence, social exclusion, deprivation, poorer quality of life and lower life expectancy (Balogh et al., 2008). People with intellectual disability and ASD are known to have poorer physical health compared with the general population and more unmet health needs (O'Hara et al., 2010).

The first part of this chapter looks at the mental health of adults with intellectual disability and ASD. That is, studies on mental health and problem behaviour that have looked at measures other than prevalence of psychiatric disorder. In addition to this research, a body of literature has developed that explores what life is like for people with intellectual disability and/or ASD. A range of methods have been used from autobiography; qualitative and ethnographic research; case reports and series to quantitative and comparative follow-up studies (Howlin, 2000). The second part of this chapter describes studies that have measured the social functioning of adults with intellectual disability and ASD.

Mental health of adults with intellectual disability and ASD

There is little evidence on the prognosis for adults with intellectual disability and ASD who have mental health problems (Prasher, 1999; McCarthy & Kannabiran, 2010). There are relatively few studies on interventions and even fewer on long-term outcomes (Davis et al., 2008; Young & Chesson, 2006). In an era when mental health service research is focussed on recovery models, little is known about how this approach applies to people with intellectual disability and/or ASD (Banks et al., 2008; Care Services Improvement Partnership et al.,

2007). It is not clear whether mental health service users with intellectual disability and ASD have more problems than those without ASD when they are referred to services. It is also not known whether their mental health problems are more or less likely to respond to treatment.

In one of the few studies to explore the incidence of mental health problems in adults with intellectual disability there was no difference between those with and without ASD on rates of recovery from mental health problems (Melville et al., 2008). However, those with ASD were significantly less likely to recover from problem behaviours than those without ASD.

Much of the early research on clinical outcomes for adults with intellectual disability and mental health problems focussed on inpatient admissions (Hemmings, 2010). These studies appeared to show that adults with intellectual disability were admitted to inpatient units more often than those without intellectual disability and stayed in them longer, however later studies did not find these differences (Chaplin, 2004). Admission rates of adult community mental health service users to inpatient care have been found to be as low as 5% over 12 months (Hackerman et al., 2006).

Studies on the mental health of adults with intellectual disability and ASD tend to measure prevalence of psychiatric disorder or specific problems rather than broader constructs of mental health or well-being. Many studies have found an association between severity of intellectual disability and psychiatric symptoms but the nature of this relationship is unclear (Hove & Havik, 2010). Factors found to predict a greater number of problems include severe intellectual disability, being female and not living with family (Jones et al., 2008).

There is some evidence that individuals with ASD exhibit a higher number and more severe symptoms of psychiatric disorder than those without ASD, particularly for depression and anxiety (Gadow et al., 2004; Gjevik et al., 2010; Kim et al., 2000; Matson et al., 2010; Mayes

et al., 2011a). Studies have also found a positive association between number of ASD traits and symptoms of depression and anxiety (Kanne et al., 2009b).

The most commonly cited studies that have compared the mental health of individuals who have intellectual disability and with and without ASD were on children and adolescents (Bradley et al., 2004; Bradley & Isaacs, 2006; Brereton et al., 2006; Hill & Furniss, 2006). They tended to focus on those with severe intellectual disability and found that participants with ASD had higher scores for attention deficit hyperactivity disorder, anxiety, depression and mania on standardised measures than those without ASD.

Table 4.1 describes studies that have compared the mental health of adults who have intellectual disability with and without ASD. Research on the prevalence of mental health problems in individuals with intellectual disability, described in Chapter 3, reported equivocal results.

Table 4.1: Studies on the mental health of adults with intellectual disability & ASD

Study	Participants	N ASD & ID	N ID	Measure of mental health	Overall results for those with ASD
La Malfa et al., 2007	Adults with severe ID. ASD group assignment made according to cut-offs for ASD on PDD-MRS, plus DSM-IV/ICD-10 criteria review for doubtful cases	41	49	DASH-II	Significant correlations between PDD-MRS scores & DASH-II subscale scores for depression, schizophrenia & mania ($p<0.05$).
LoVullo & Matson, 2009	Adults with severe ID. Compared: ASD + ID vs. ID vs. ASD + ID + psychopathology. Clinical diagnosis of ASD/no ASD using DSM-IV/ICD-10 checklist.	162	151	ASD-CA	Significant differences for ASD+ID vs. ID on total, anxiety & depression scores. No significant differences between ASD+ID & ASD+ ID+psychopathology groups
Smith & Matson, 2010	Adults with severe ID. Compared: ASD+ID vs. ID vs. ASD+ID+ epilepsy vs. ID+epilepsy groups matched on age/gender/ethnicity/ID severity. Clinical diagnosis of ASD/ no ASD using DSM-IV/ICD-10	50	50	ASD-CA	Higher scores for anxiety subscale between ASD + ID + epilepsy & ID + epilepsy and for depressive subscale between ASD + ID + epilepsy & ID (both $p<0.05$)
Charlot et al., 2008	Adult inpatients with depression. Matched on age/gender /ID severity. Clinical diagnosis of ASD/no ASD according to DSM-IV criteria.	13	40	MASS	Higher mean number of anxiety symptoms: 12 vs. 10, $p=.05$. No differences on individual symptoms or clusters, except for decreased sleep ($p=0.05$).

ASD-CA= *ASD-Comorbidity for Adults scale*, DASH-II=Diagnostic Assessment for the Severely Handicapped-II, MASS= Mood & Anxiety Semi-Structured Interview for Patients with ID, PDD-MRS= Pervasive Developmental Disorder in Mental Retardation Scale

By contrast, the studies reported in Table 4.1, which used continuous measures of symptoms and symptom severity, were more consistent. They appear to show that adults with intellectual disability and ASD have poorer mental health than those without ASD across a range of measures. As with the earlier studies on children and adolescents, depression and anxiety scores were often significantly higher for participants with ASD.

However, it should be noted that none of these studies on adults used a standardised diagnostic assessment to confirm whether those in the ASD group did – and those in the 'no ASD' group did not – have ASD. In addition, most only included participants with severe intellectual disability.

There is evidence that adults with intellectual disability and ASD tend to score highly on scales that measure symptoms of mental health problems. Studies that rely on cut-off scores of rating scales to ascertain psychiatric 'caseness' without a comprehensive diagnostic assessment may overestimate the rate of psychopathology among adults with ASD and intellectual disability. On the other hand, studies that only measure the prevalence of psychiatric disorder may not adequately capture differences in the mental distress experienced by participants with and without ASD. More studies across the range of intellectual disability severities are needed.

Problem behaviours among adults with intellectual disability and ASD

The estimated prevalence of challenging behaviour among individuals with intellectual disability ranges from 1-2% up to 40-50% depending on the definitions applied, population studied and type of challenging behaviours recorded (Holden & Gitlesen, 2006; O'Brien, 2003). Research has linked variations in the presence of challenging behaviour to severity of intellectual disability, language abilities, age (highest in late adolescence), gender (greater

prevalence among males), cause of intellectual disability, presence of physical health problems including epilepsy, life events and socio-economic status (Hemmings et al., 2008a; O'Brien, 2003; Taggart et al., 2011). Other studies have found no differences in gender, but some differences by degree of intellectual disability (Davidson et al, 2003). Bihm et al. (1998) found that age was positively correlated with aggression, epilepsy was negatively correlated it and that aggression was related to psychosis and depression.

There is evidence that challenging behaviour is also highly prevalent among individuals with ASD (Holden & Gitlesen, 2006). Aside from the repetitive and restricted behaviours that are characteristic of people with ASD, specific problems associated with ASD include aggression, self-injurious behaviour and hyperactivity (Levy et al., 2009; Tsiouris et al., 2003a).

A number of studies have found higher rates of challenging behaviour among individuals with intellectual disability and ASD compared to those with intellectual disability alone (Bradley et al., 2004; Holden & Gitlesen, 2006; McCarthy et al., 2010; Rojahn et al., 2010). However, other studies found no significant difference in prevalence between those with and without ASD when participants were matched on age, gender and severity of intellectual disability (Melville et al., 2008).

Relationship between psychiatric disorder and challenging behaviour

There is conflicting evidence on whether there is an association between problem behaviours and psychopathology in people with intellectual disability and ASD (Myrbakk & Vontetzchner, 2008; Rojahn et al., 2004). McCarthy et al (2010) found differences between psychiatric diagnoses according to presence of ASD in mental health service users with intellectual disability and challenging behaviour. However there was no association between

psychopathology and challenging behaviour once age, gender and severity of intellectual disability were controlled for.

Social functioning of adults with intellectual disability and ASD

Adults with intellectual disability are said to be among the most vulnerable and socially excluded individuals (Department of Health, 2001b). Many are unable to live independently or hold down a job. It is thought that round 60% of adults with intellectual disability live with their families (Department of Health, 2001b) and only 17% are employed (Foundation for People with Learning Disabilities, 2007). It is not clear whether those who intellectual disability and ASD have comparatively poorer social functioning than those with intellectual disability alone.

Much of the focus of research on the social functioning of people with intellectual disability has been on community housing; an important issue given the changes that have occurred in providing accommodation for these individuals (Felce et al., 2008; Felce et al., 2011). The most commonly used measures are community participation, choice, adaptive behaviour and challenging behaviours (Kozma et al., 2009). The social functioning of people with intellectual disability appears to be associated with IQ and level of adaptive functioning (Felce et al., 2011).

Research on adults with ASD began in the late 1960s when those children who were among the first to be diagnosed with autism reached adulthood. Studies were mainly descriptive but found indications that adult outcome, in terms of social functioning, for most of those with ASD was poor and appeared to be related to IQ and verbal skills (Lockyer & Rutter, 1969; Lotter, 1974; Rutter et al., 1967). Kanner (1971) explored the 'destinies' of the original sample that defined the clinical criteria for autism and surmised that those who were not

admitted to hospital and lived in a supportive environment had a better outcome. Lotter (1974) commented that '*...it remains easier to predict a poor outcome than a good outcome*' (pp. 273).

Research that followed largely confirmed these earlier findings. Although, in general, outcomes for adults with ASD appear to improving over time (Howlin, 1997; Howlin & Goode, 1998). A review in 2000 of outcome in adult life for those with high-functioning ASD identified six studies (Howlin, 2000). Results were 'extremely variable', however most studies reported low rates of employment (maximum 44%), independent living (maximum 50%) and 'good outcome' (maximum 44%). The review found there was a suggestion of increased mortality among people with ASD (further increased for those with low IQ) but no evidence of an increase in forensic issues (Howlin, 2000). Adult outcomes for those with the full spectrum of ASD have not been systematically studied (Levy & Perry, 2011).

Since the review by Howlin (2000), described above, there has been an increasing interest in adult outcomes for people with ASD and a number of further studies on the social functioning of adults with ASD have been published. These are detailed in Table 4.2; as found previously the methods and results have varied widely.

A significant number of these studies concentrated on people with high-functioning ASD. Many looked at the impact of IQ on social functioning but few focused on those with intellectual disability to explore whether these associations are present among those with low IQ (particularly below 50). In addition, many did not include a comparison group so it is not clear whether these individuals had poorer social functioning compared to those without any other disorder or with intellectual disability alone. Other studies included a comparison group of participants with a different disorder or different types of ASD.

Table 4.2: Studies on the social functioning of adults with ASD

Study	Participants	Comparison group	Measure(s)	Source of data	Overall results for those with ASD
Engstrom et al., 2003	16 adults with Asperger syndrome or high-functioning ASD (DSM-IV criteria) (IQ>70)	None	Employment, relationships, type of residence, needs. Composite score of social functioning based on Lotter's criteria*	Clinician interview, participant interview, Camberwell Assessment of Need (CAN)	Good to fair social functioning in majority (87%).
Farley et al., 2009	41 adults who had ASD without ID (confirmed by ADI-R & ADOS)	None	Employment, ability to travel independently, type of residence, relationships, level of support required (see Engstrom's definition). Howlin et al. 2004 criteria*	Vineland Adaptive Behaviour Scales, parent interview	Fair to very good social functioning for majority (83%).
Renty & Roeyers, 2006	58 adults who had ASD without ID (according to DSM-IV criteria)	None	Employment, type of residence, relationships, quality of life.	Quality of Life Questionnaire for adults with intellectual disability (QoLQ), Interpersonal Support Evaluation List, CAN	Low levels of independence & employment
Howlin et al., 2004	68 adults with ASD & IQ>50 (confirmed in adulthood by ADI-R)	None	Education, employment, friendships, type of residence. Composite score of social functioning.*	ADI-R, parent interview, case records.	Mostly poor social functioning (58%). Significantly poorer for those with IQ of 50-69
Barnard et al., 2001	450 adults with ASD (according to parent-reported diagnoses which were not assessed)	None	Employment, activities, type of residence	Parent interview	Low levels of employment, activities & independence
Eaves & Ho, 2007	48 young adults with ASD (according to Rutter criteria) (38 with ID)	None	Quality of life, employment, type of residence, friendship, independence, satisfaction with services. Howlin et al. 2004 criteria*	Parent interview	Fair to very good social functioning for majority (54%), none with very poor.
Saldana et al., 2009	74 adults with ASD (clinical diagnosis)	None	Quality of life, employment, health, social network.	Parent interview, Comprehensive Quality of Life Questionnaire, social/language DAS items, CARS, ICAP	Poor quality of social interaction, low levels of structured activity (16%) & independence
Green et al., 2000	20 male adolescents with Asperger syndrome (IQ>70) (according to ICD-10 criteria)	20 males with conduct disorder	Social & emotional functioning: Independence, interpersonal difficulties, relationships. Psychiatric functioning	Isle of Wight Semi-structured Informant & Child Interviews, Social & Emotional Functioning interview	Poorer social functioning than comparison group, no correlation between social functioning & IQ

Study	Participants	Comparison group	Measure(s)	Source of data	Overall results for those with ASD
Howlin et al., 2000; Mawhood et al., 2000	19 males who had ASD (according to Rutter criteria) without ID (IQ>70)	20 males with developmental language disorders (matched on non-verbal IQ)	Education, employment, friendships, type of residence, language, independence, stereotyped behaviours, relationships, cognitive functioning. Composite score of social functioning.*	ADI-R, ADOS, Socio-Emotional Functioning Interview & Vineland Adaptive Behavior Scales	Poorer social functioning (problems with jobs, relationships, & independence). 74% had severe social difficulties
Marriage et al., 2009	45 adults diagnosed with ASD (according to DSM-IV) in childhood (12 had ID)	35 adults diagnosed with ASD after age of 18 (1 had ID)	Education, vocation, independence, social, intimate relationships	Case note review, Australian Scale for Asperger's Disorder, AQ, Child Symptom Inventory. ADI-R & ADOS	Poorer social functioning for those with ASD & ID compared with ID alone
Billstedt et al., 2005	78 adults with autism (DSM-IV criteria & DISCO) (62 with ID)	42 adults with atypical autism (36 with ID)	Type of residence, relationships, Lotter's criteria of outcome*	Parent interview, DISCO, Global Assessment of Functioning (GAF)	Poor social functioning for majority (89%), no difference between groups
Cederlund et al., 2008	70 adult males with autism or atypical autism (according to DSM-III & DISCO) (67 had ID)	70 adult males with Asperger syndrome (IQ>70)	Type of residence, Outcome rating based on Lotter's criteria*	DISCO, GAF, Vineland Adaptive Behavior Scales	Poor social functioning for majority. Better for those with AS.
Esbensen et al., 2010	79 adults with ASD & ID (confirmed by ADI-R)	70 adults with Down syndrome (matched on age)	Type of residence, social contact with friends, employment, health, functioning. Howlin et al. 2004 criteria*	Parent interview, revised Barthel Index, Vineland Screener Scale, Scales of Independent Behavior-Revised	Low levels of independence & contact with friends. Poorer social functioning.
Totsika et al., 2010	Adults with ID & ASD aged 50 years & over (DAS triad of impairments) (65 with matched adaptive behaviour skills)	Adults with ID aged over 50 years (65 in matched group)	Domestic, social and community activities	Index of Community and Index of Participation in Domestic Life, ABC, PIMRA or PAS-ADD	Lower levels of activity but no differences between matched groups
Felce et al., 2011	158 adults with ID & ASD (triad of impairments on DAS) in staffed community housing	269 adults with ID in staffed community housing	Challenging behaviour, independence variety/frequency of social & community activities, constructive activities	ABC, AAMR ABS, DAS	No difference in social functioning between groups
Beadle-Brown et al., 2009	51 adults with severe ID & ASD (according to ICD-10 criteria)	21 adults with severe ID	Life satisfaction, community satisfaction, recreation satisfaction, job satisfaction, challenging behaviour,	Lifestyle Satisfaction Scale, Schedule of Handicaps Behaviours & Skills, AAMR ABS, Leiter International Performance Scales,, QoLQ, Reynell Language Development Scales	ASD was not a significant predictor of quality of life once challenging behaviour & IQ were accounted for

*See Appendix V. AAMR ABS=American Association on Mental Retardation Adaptive Behavior Scale, ABC= Aberrant Behaviour Checklist , ADI=Autism Diagnostic Interview, ADOS=Autism Diagnostic Observation Schedule, DAS= Disability Assessment Schedule, DISCO=Diagnostic Interview for Social & Communication disorders, ICAP=Inventory for Client & Agency Planning PAS-ADD= Psychiatric Assessment Schedule for Adults with Developmental Disorders, PIMRA= Psychopathology Instrument for Mental Retarded Adults, QoLQ=Quality of Life Questionnaire.

Rates of unemployment for those with ASD ranged from 24 to 98%. Many left school without qualifications and only 8 to 20% were living independently. One study found that 24% of all those with ASD were not engaging in any meaningful activity and 31% were not involved in any social activities (Barnard et al., 2001).

Some of these studies were able to explore associations between intellectual and social functioning for adults with ASD. In Eaves and Ho's study (2007) verbal IQ in childhood was the best predictor of social functioning score which also correlated with performance IQ. Another study found that low IQ and low verbal skills in childhood predicted social functioning but poor and very poor social functioning definitions include these items (Billstedt et al., 2005). Renty & Roeyers (2006) found that higher quality of life scores were significantly associated with having a job/being a student, higher perceived informal support and lower of unmet needs.

In a study that compared adult males with autism to those with Asperger syndrome (AS), most participants had poor social functioning (Cederlund et al., 2008). Those with AS had significantly better social functioning. Among those with autism, none had good social functioning, 5% had fair social functioning and only 8% of those over 23 lived independently. The majority of this group had intellectual disability. Participants with autism had significantly lower Global Assessment of Functioning (GAF) scores than those with AS; GAF score was significantly associated with IQ.

Marriage et al. (2009) compared adults diagnosed with ASD in childhood and those who were diagnosed after 18 years of age. Of the participants diagnosed as children, those with intellectual disability scored lower than those without intellectual disability on all measures except for intimate relationships.

In Howlin et al.'s study (2004) there was not a significant correlation between IQ and social functioning. However, a sub-analysis compared participants whose IQ was 50-69 with those whose IQ was over 70. Those in the lower IQ group scored significantly higher (indicating a poorer social functioning) on residential status, educational level, level of work and total rating of social functioning.

Few studies directly compared adults who had intellectual disability with and without ASD. A series of studies from Wales has explored the mental health and social functioning of adults with intellectual disability. Sub-analyses of those with ASD (as assessed using items on the Disability Assessment Schedule (DAS; Holmes et al., 1982) relating to the ASD triad of impairments) have been carried out. Totsika et al. (2010) compared quality of life for older adults with and without ASD. Participants with ASD were involved in a significantly lower number of domestic, social and community activities than those without ASD. They also spent a lower proportion of their time engaged in any activity (39% vs. 59%). Those with ASD had significantly more behaviour problems (a higher mean score on the Aberrant Behavior Checklist) than those without ASD.

However, in a sub-analysis of those with matching adaptive skills there were no significant differences between those with and without ASD on any quality of life measure or problem behaviours (Totsika et al., 2010).

A recent study from this series looked at adults with intellectual disability who lived in staffed community housing (Felce et al., 2011). Participants with ASD were more likely to have severe challenging behaviour (36% vs. 15%), had higher levels of problem behaviour and lower levels of adaptive behaviour than those without ASD. When participants were matched on adaptive behaviour, there remained significant differences in levels of problem behaviour and the proportions with challenging behaviour. Measures investigated included

variety/frequency of social and community activities, household independence, engagement in constructive activities. There were no significant differences between those with and without ASD on any measure. The authors of these studies acknowledged limitations with regards to the way participants were categorised into those with and without ASD (Felce et al., 2011; Totsika et al., 2010).

The 'Camberwell cohort' were a total population sample of children with severe intellectual disability and/or ASD in South London, this group was followed up as adults to explore their life satisfaction (Beadle-Brown et al., 2009). Participants with ASD had lower levels of community satisfaction than those without ASD but there was no difference on any other measure. The only childhood predictor of quality of life among the whole sample was independent living skills. Of the measures taken when participants were adults the most important factors associated with quality of life were challenging behaviour and IQ.

Esbensen et al. (2010) compared individuals with ASD and intellectual disability to those with Down syndrome. Few participants had high or very high levels of independence. Most of those with ASD had low or very low levels of independence where as those with Down syndrome tended to be classed as having moderate or low levels. Predictors of social functioning for those with and without ASD were total functional abilities and service receipt. Severity of intellectual disability and maladaptive behaviours were not significant predictors of social functioning.

This study found that those accessing mental health services had poorer social functioning and concluded that: *"It will be important for future researchers to examine the best ways to assess psychological and psychiatric needs among adults with autism spectrum disorders so that appropriate interventions can be put in place"* (Esbensen et al., 2010; pp. 287).

Although a number of the studies described above included measures of psychopathology, none looked at the social functioning of those who have mental health problems or the interaction between psychiatric disorder and social functioning. Chaplin et al. (2010b) studied 750 mental health service users with intellectual disability who had a mean age of 33 years. Half lived with their family, 37% in a supported residence and 13% lived independently. The vast majority (97%) of those living independently had mild intellectual disability. Age, level of intellectual disability and diagnoses of anxiety or personality disorder were significant, independent predictors of type of residence. Presence of ASD was not associated with type of residence although only 5% of those with ASD lived independently.

It is clear that the mental health and social functioning of people with intellectual disability and ASD varies greatly over time, geographical areas and between individuals. The evidence on which factors are significantly associated with social functioning is weak. This is because the few good quality studies in this area have included diverse populations and used a range of methods to define/diagnose ASD, collect data and measure social functioning (Levy & Perry, 2011). However, there is some consistent evidence on the characteristics that appear to be related social functioning for people with intellectual disability and ASD.

The following factors have been found to have a positive relationship with social functioning:

- IQ
- Expressive communication
- Early language skills
- Adaptive functioning
- Level of perceived informal support

The following factors have been found to have a negative relationship with social functioning:

- Severity of ASD/ASD symptoms
- Level of unmet formal support needs

It is important that studies on differences in the social functioning of adults who have intellectual disability with and without ASD explore the effect of these variables. That is, whether they are better predictors of social functioning than ASD itself or effect moderators that have a different impact on individuals with and without ASD.

Measuring the social functioning of adults with intellectual disability and ASD

Common measures for people with intellectual disability include life expectancy, physical and mental health, adaptive functioning, service contact, employment, relationships (O'Brien, 2001). Often in the literature there is a blurring of the boundaries between 'baseline' factors, 'inputs' and 'outcomes'. For example, service receipt, needs, daily living skills or cognitive functioning are used as measures of social functioning rather than independent variables that may predict it.

In Howlin's (2000) review of adult outcome for people with ASD, seven types of measure were used by the included studies: *"1) IQ, academic skills and adaptive behaviours; 2) language ability; 3) behavioural problems; 4) education and employment history; 5) independence and social relationships; 6) psychiatric history; and 7) stability of IQ over time and variables related to outcome"* (pp. 67).

The research described in this chapter also used a wide range of methods to define and measure social functioning. The most common themes were employment, education and

independence. It was standard practice for these studies to use a composite scale based on information from a range of instruments rather than any direct data collection or use of an existing measure of social functioning. Many of the measures were based on criteria developed by Howlin (2004) or Lotter (1974).

There are some limitations to these measures particularly for adults with intellectual disability. For example, Lotter's definition of poor social functioning included 'obvious severe handicap' therefore those with intellectual disability are more likely to fall into these categories. Most mental health service users with intellectual disability would score poor or very poor on these criteria (Levy & Perry, 2011).

There could also be problems applying the two criteria developed by Howlin to people with intellectual disability, ASD and mental health problems. In the earlier criteria (Howlin et al., 2000), the composite score included measures of autistic behaviours and language therefore those with ASD would be more likely to score higher and appear to have poorer social functioning if compared to a group without ASD. To date there is little evidence on the psychometric properties of these measures (Billstedt et al., 2005; Levy & Perry, 2011). The criteria used by Howlin et al. (2004) have been found to have intra-class correlation of 0.97 (Farley et al., 2009). Marriage et al (2009) acknowledged that such methods *"should be considered more qualitative than quantitative"* (pp. 327).

In addition to social functioning, studies have used quality of life measures. Quality of life domains have been identified as social inclusion, physical well-being, interpersonal relationships, material well-being, emotional well-being, self-determination, personal development and rights (Schalock et al., 2002). The questionnaire used in the *Ignored or Ineligble?* report was reviewed by a panel of parents of adults with ASD (Barnard et al.,

2001). But on the whole, previous research has not been based on measures developed by asking adults with intellectual disability and ASD what they think is important.

Conclusion on the social functioning of adults with intellectual disability and ASD

In early studies, adults with ASD appeared to have generally poor life outcomes. More recent research found that their social functioning was better than expected. IQ and verbal skills appear to be the most significant predictors of social functioning and there is evidence that those with intellectual disability or more severe ASD do less well in adult life.

There are few recommendations on what might be done to improve the social functioning of adults with intellectual disability and ASD. Howlin (2000) suggested that although life for people with ASD appears to have improved over time, it is likely this is due to less institutionalisation and more opportunities. Stating: *"...there is no evidence to suggest that long-term outcome can be dramatically improved following the implementation of any particular intervention programme"* (pp. 78).

Most factors associated with poorer social functioning are those that tend not to change such as IQ and severity of ASD symptoms. However it is possible that early recognition and intervention could improve individuals' adaptive functioning and skills and that this could in turn lead to better social functioning. More research is needed on the relationships between socio-demographic/clinical characteristics, psychopathology, challenging behaviour and social functioning.

It is currently not clear whether adults with intellectual disability and ASD have better or poorer social functioning than those with intellectual disability alone. The social functioning of people with intellectual disability and ASD who have mental health problems is even more poorly understood (Pridding & Tomasoni, 2006).

Studies should be prospective, longitudinal and population-based but given the difficulties carrying out these types of studies, clinic-based, cross-sectional studies can provide a valuable snapshot of individuals' lives (Engstrom et al., 2003; Elison et al., 2010). An improved understanding of the characteristics that appear to predict social functioning and the course of mental health problems would aid the provision of services and interventions for adults with intellectual disability and ASD.

Chapter 5: Services and interventions for people with intellectual disability, ASD and mental health problems

People with intellectual disability and ASD access a broad range of largely community-based services provided by the public, private and voluntary sectors. The common aim of these services is to improve the lives and outcomes of individuals. But, since resources are scarce they also strive to be as efficient and cost-effective as possible. This chapter looks at the evidence-base for the provision of services and interventions for adults with intellectual disability and ASD as well as data on their service use and its impact on mental health and outcome. The focus is on policy and health service provision in England.

Policy

Valuing People: A New Strategy for Learning Disability for the 21st Century focussed on independence, choice, equality and inclusion (Department of Health, 2001b). The White Paper maintained that individuals with intellectual disability have the same right to access mainstream health services as the rest of the population and should be able to do so whenever possible. This would be implemented through the National Service Framework for Mental Health, the Care Programme Approach and Health Action Plans. Other issues raised included a lack of outcome measures with which to compare the health of people with intellectual disability to the rest of the population and the over-use of psychotropic medication for those with challenging behaviour. Valuing People acknowledged that people with intellectual disability and ASD may have different needs compared with the rest of the intellectual disability population but stated that "*the majority will not need autism specific services*" (Department of Health, 2001b, pp. 101).

The explicit exclusion of people with high-functioning ASD from Valuing People led to more intense lobbying for better service provision for people with ASD; culminating in the passing

of the Autism Act, 2009. A number of accompanying documents were published including the National Autism Strategy (Department of Health, 2009a; 2010b), a National Audit Office report (National Audit Office, 2009b) and good practice guidance (Department of Health, 2009b). As with Valuing People, these policies focus on improving access to services, independence and reducing inequality. Two clinical guidelines on the recognition and diagnosis of ASD in children and adults are in development (NICE, 2011; NICE, 2012). Other significant changes have been made; for example the *NHS Standard Contract for Mental Health and Learning Disabilities* now explicitly states that services must make reasonable adjustments for adults with ASD in accordance with the Disability Discrimination Act (Department of Health, 2010b).

Although Valuing People recognised the needs of adults with intellectual disability and ASD there was little specific mention of how those needs might be met. Meanwhile the recent ASD policies and documents have largely focussed on those with high-functioning ASD. Perhaps because, as discussed in previous chapters, it is not clear whether people with both intellectual disability and ASD are at increased risk of mental health problems or have poorer outcomes, therefore they rarely receive specific mention in either intellectual disability or ASD policy. Despite evidence that they have increased and more complex needs than the general population, people with intellectual disability and/or ASD remain excluded from or unmentioned in mainstream documents such as clinical guidelines and National Service Frameworks (Care Services Improvement Partnership et al., 2007).

Services and interventions

People with intellectual disability and ASD are likely to need input from a range of services at some point during or throughout their lives (Department of Health, 2001b; Department of Health, 2010b). There is recognition that access to services is more limited once individuals

reach adulthood (National Audit Office, 2009b). However with low levels of employment and many people being unable to live independently, the need for support increases as individuals approach 18 (Department of Health, 2009b; Higgins, 2009).

As set out in government policy, adults with intellectual disability and ASD should be able to access the same range of health services as the rest of the population. Intellectual disability services provide support for people to access mainstream mental health services where possible. However, it is acknowledged that mainstream services and community intellectual disability services do not always have the expertise or resources to support people with additional complex needs and that in some circumstances specialist input is required (LeMesurier et al., 2007). As such there are several community and inpatient assessment and treatment services specifically for adults with intellectual disability who have mental health problems and/or challenging behaviour.

These services are not consistently or comprehensively provided throughout the UK (Chaplin et al., 2010a). In areas where there is limited specialist provision, people with intellectual disability and mental health problems are often said to "fall between two stools" (Doody, 2001). This happens when neither intellectual disability services nor mainstream mental health services have the necessary expertise to provide for them. This type of situation is even more common for adults with ASD (Barnard et al., 2001; Higgins, 2009). Those who are eligible should receive the same provision as adults with intellectual disability. However, it is not clear whether adults with intellectual disability and ASD are successfully accessing or benefitting from these services. Furthermore, specialist ASD services may be reluctant to accept individuals with intellectual disability because they consider this group are already provided for by intellectual disability services.

There is little evidence on the best ways to provide mental health services to adults with intellectual disability (Hemmings, 2008). Evaluation studies on service models and interventions rarely specifically mention whether they included participants with ASD (e.g. Coelho et al., 1993; Dowling et al., 2006; Kerr et al., 2005; Lennox et al., 2007; Martin et al., 2005; Oliver et al., 2005; Willner et al., 2002). Research does not often consider whether there might be differences between those with and without ASD at baseline or with regards to outcome. Few studies take into account whether ASD, severity of intellectual disability or presence/absence of psychiatric disorder (among other factors) might confound their results. Evidence that a range of variables appear to be associated with outcome does not appear to have had much influence on the design or analysis of research (Courtemanche et al., 2011).

Service consumption of adults with intellectual disability

Evidence on the cost of intellectual disability to the economy is weak (Romeo & Molosankwe, 2010). At the time of the World Health Report of 2001 there were no estimates for the overall disease burden of intellectual disability (WHO, 2001). The Department of Health (2001b) has estimated that total UK expenditure on health and social services for people with intellectual disability is around £3 billion a year.

A high proportion of the social care costs associated with intellectual disability are accounted for by residential placements (Felce et al., 2008; Hallam et al., 2006; Polder, 2002; Strydom et al., 2010). High service use and expenditure on adults with intellectual disability has been associated with age, challenging behaviour, mental health problems, more severe intellectual disability, higher levels of need and white ethnicity (Harrington & Kang, 2008; Kang & Harrington, 2008; Knapp et al., 2005; Strydom et al., 2010). Other factors related to different types of service use include type of residence and number of service users per residence (Knapp et al., 2005).

Mental health service consumption[2] of adults with intellectual disability

There has long been evidence that a large amount of mainstream mental health service consumption is accounted for by a relatively small number of service users (Lavik, 1983). Despite this, exploring the characteristics of those with intellectual disability who get referred to services and the level of services they use has not been a priority for mental health research (Driessen et al., 1997; Spiller et al., 2007).

As described in Chapter 3, there is evidence that mental health services users are more likely to be male and tend to be younger than the rest of the intellectual disability population (Bhaumik et al., 2008b; Bouras et al., 2003). It is not clear whether this is due to actual differences in the prevalence of mental health problems or referral bias. Other studies have not found gender to be associated with increased likelihood of referral and found that older people were more likely to referred to specialist mental health services (Driessen et al., 1997).

There appears to be some consensus that users of specialist mental health services are more likely to have mild intellectual disability (Spiller et al., 2007). Although this is not found in all studies (Bhaumik et al., 2008b). Factors that have been identified as predictors of mental health service consumption among adults with intellectual disability include age, type of residence, length of service use, severity of behaviour problems, severity of intellectual disability and presence of a psychotic disorder (Driessen et al., 1997; Jacobson, 1998; Knapp et al., 2005; Spiller et al., 2007).

Services consumption of adults with ASD

The National Audit Office (2009b) acknowledged that while it is known that adults with ASD use a wide range of services, precise data on their service consumption is very limited. Only a

[2] For the purposes of the thesis *mental health services* include psychiatry, psychology & behaviour support services.

few studies that included information on the service use of adults with ASD can be identified (Knapp et al., 2007). Many focused on certain types of service (such as employment) and the costs of providing them (Cimera & Cowan, 2009). A study in California on service use among individuals with developmental disorders found that those with ASD were more likely to be receiving support and respite services than those with other types of disability including intellectual disability (Kang & Harrington, 2008; Harrington & Kang, 2008).

A more recent study, also from the United States, looked at service use after individuals with ASD left school (Shattuck et al., 2011). Of the 410 participants, 35% were receiving mental health services but only 23.5% were accessing other medical services. Almost 40% received no services and this was associated with Afro-Caribbean ethnicity, low income and higher levels of functioning. Although participants were categorised into four levels of 'functional mental skills' it was not clear whether or how these related to intellectual disability. Level of functioning was not associated with receipt of mental health services. Furthermore, gender, age, verbal ability and type of residence were not associated with service use.

Service consumption of adults with intellectual disability and ASD

Knapp et al. (2009) suggested that while around 55% of people with ASD also have intellectual disability, these individuals account for 66% of the annual cost of ASD to the UK economy. The estimated lifetime cost for people with ASD and intellectual disability is 50% greater than for those without intellectual disability. Presence of ASD has been found to be a strong predictor of hospital admission, medication use and problem behaviours in adults with intellectual disability (Cowley et al., 2005; Tsakanikos et al., 2007; Underwood et al., 2010).

As with the general intellectual disability population, expenditure for those who also have ASD is largely accounted for by residential costs (Knapp et al., 2009). However, published

data on adults with intellectual disability and ASD for types of service use other than accommodation is difficult to obtain (Knapp et al., 2007).

In Knapp et al. (2009), adults with intellectual disability and ASD living with family were estimated to have high levels of day centre, college and respite care use. This study provided some evidence that adults with intellectual disability and ASD have higher support costs than those without intellectual disability. However, it is still unclear whether this is due to the presence of intellectual disability, ASD or the combination of both conditions.

Only one study could be found that directly compared the service use of adults who have intellectual disability with and without ASD. Age-matched groups of 70 adults with ASD and 70 adults with Down syndrome (DS) were compared (Esbensen et al., 2010). Participants with ASD were significantly more likely to be receiving mental health and personal care services than those with DS. However those with ASD were significantly less likely than those with DS to be receiving recreational, transport, employment services or income support. Service receipt was significantly associated with social outcomes for both groups (see Chapter 4 for more details on this study).

Interventions

There are a range of interventions that are used for individuals with intellectual disability or ASD who have additional mental health or behavioural problems. These are most often the same as (or adapted versions of) those developed for the general population. This section explores the use of interventions commonly provided for adults by NHS services in the UK.

Medication

Rates of medication use among those with intellectual disability and/or ASD are high compared with the general population; with antipsychotic medication being the most

commonly prescribed (De Kuijper et al., 2010; Matson & Neal, 2009). This should not necessarily be taken as an indication that psychotic disorders are the most prevalent mental health problems among these individuals since antipsychotics are likely to be prescribed for a wide range of other disorders (Paton et al., 2011).

Although antipsychotic, anticonvulsant and mood stabilising medications are not licensed for such use, they are often prescribed for behavioural problems in the absence of any psychiatric disorder (Deb et al., 2008; De Kuijper et al., 2010). Despite this widespread use the evidence base for psychotropic medication to treat behaviour problems is extremely weak (Deb & Unwin, 2007; Matson & Neal, 2009). Among antipsychotics, risperidone has been found to be effective in some studies (McDougle et al., 1999) with others finding no advantage over placebo (Tyrer et al., 2008). There are concerns about the level of benzodiazepine use among adults with intellectual disability and/or ASD, particularly when prescribed on a PRN (as required) basis (De Kuijper et al., 2010; Robertson et al., 2000).

Psychotropic medication use in individuals with intellectual disability has been found to be associated with presence of ASD, communication problems, challenging behaviour, presence of a psychiatric disorder, type of residence and severity of intellectual disability (de Bildt et al., 2006; Holden & Gitlesen, 2004; Paton et al., 2011; Robertson et al., 2000; Tsakanikos et al., 2007). In addition some research has found relationships between medication and gender (De Kuijper et al., 2010).

Studies have found that 40-64% of individuals with ASD are prescribed at least one psychotropic medication with most individuals receiving more than one and some taking up to seven different drugs (Esbensen et al., 2009; Weeden et al., 2011). There is also evidence that when people with ASD are prescribed psychotropic medications they end up taking them for long periods of time (Esbensen et al., 2009). Studies on the effectiveness of psychotropic

medication have found high rates of non-response among those with ASD and challenging behaviours (Beherec et al., 2011).

There is evidence to suggest that adults with intellectual disability and ASD are more likely to be taking psychotropic medication than those with intellectual disability alone (Tsakanikos et al., 2006). LoVullo & Matson (2009) found that 71% of those with intellectual disability, ASD and psychopathology were taking medication, this was higher than those with intellectual disability only (0%) and those with intellectual disability and ASD (16%) but the report did not provide any data on people with intellectual disability and psychopathology.

Morgan et al. (2003) reported that 52% of those with intellectual disability and ASD were prescribed psychotropic medication but did not compare this to the rate for those without ASD. Melville et al., (2008) found that adults with intellectual disability and ASD were more likely to be on antipsychotic medication than those without ASD; although this difference was not statistically significant. A randomised controlled trial of antipsychotic medication for challenging behaviour in adults with intellectual disability found no evidence that those with ASD had a different response to those without ASD (Tyrer et al., 2008).

Behavioural, educational, psychological and social interventions

Data on the effectiveness of pharmacological treatment continues to throw doubt on the appropriateness of medication particularly for behaviour problems in adults with intellectual disability and/or ASD (McGillivray & McCabe, 2004; Romeo et al., 2009). As a result, there is demand for increased access for these individuals to evidence-based behavioural, educational, psychological and social interventions (Hassiotis et al., 2009b; Matson & Neal, 2009). However, research on the effectiveness of psychosocial interventions is at an even earlier stage than that on pharmacological treatment (Gustafsson et al., 2009; Hatton, 2002; Seida et al., 2009).

Interventions most commonly used for adults with intellectual disability and ASD who have mental health problems include anger management, behavioural therapies and cognitive behavioural therapy (CBT). Naturally, there are concerns about whether adults with intellectual disability and/or ASD are able to participate in the processes required for psychological interventions like CBT (Hatton, 2002). When mainstream approaches are adapted there is additional concern about their fidelity to the original theoretical and evidence-based models (Hemmings et al., 2008b).

A survey of research on psychosocial interventions for adults with intellectual disability and/or ASD who have mental health problems identified only three systematic reviews that met the authors' inclusion criteria (Gustafsson et al., 2009). There was limited evidence for the effectiveness of specialist community services for adults with intellectual disability compared with mainstream services (Chaplin, 2004) and the use of CBT to reduce aggression (Hassiotis & Hall, 2008).

A review of psychosocial interventions for ASD identified 14 systematic reviews that included adults (Seida et al., 2009). The studies included in these reviews did not appear to have been designed for those with additional psychopathology but focussed on problem behaviours or symptoms of ASD. Very few were high quality randomised controlled trials and there was little information on whether they included participants with and/or without intellectual disability.

In the UK, most psychosocial interventions for adults with intellectual disability and ASD who have mental health problems are delivered by psychologists and behaviour support specialists. Few of the studies on mental health service consumption cited in this chapter distinguished between psychiatric and psychological/behavioural services. Those that did

appeared to show that adults with intellectual disability were more likely to have access to a psychiatrist than a psychologist and that psychology service use was associated with age, severity of intellectual disability and challenging behaviour (Jacobson, 1998; Knapp et al., 2005).

Conclusion on service provision for adults with intellectual disability and ASD

Adults with intellectual disability and ASD remain overlooked in the development and evaluation of mainstream policies, services and interventions. Their specific mental health needs are often not considered with regards to specialist intellectual disability or ASD provision. More evidence is needed on identifying service users at increased risk of mental health problems and which factors impact on their outcomes.

Specialist services for adults with intellectual disability and/or ASD in the UK are highly varied (Chaplin et al., 2010a; Department of Health, 2007a). Services for adults with high-functioning ASD remain largely separate from services for adults with intellectual disability who are expected to provide for those with low-functioning ASD. However, there is growing acknowledgement that even specialist intellectual disability services find it difficult to meet the needs of people with ASD who have mental health or behaviour problems (Mills & Francis, 2010).

Many studies describe service consumption as being associated with needs-related characteristics of individuals (e.g. whether they have additional mental health problems or severity intellectual disability) (Kang & Harrington, 2008; Shattuck et al., 2011). However, there are few data on whether there is a direct link between standardised measures of need and level of service consumption (Knapp et al., 2005).

There is little data on the service and intervention use of adults with intellectual disability but some evidence that there are differences between those with and without ASD. The evaluation of service models and interventions for adults with intellectual disability and/or ASD remains challenging. This could be in part because the characteristics of service users, the needs of specific groups of service users and the impact of these on outcomes are not well understood.

Chapter 6: Aims, objectives and hypotheses

Summary of the literature review

The accurate assessment of ASD, intellectual disability and mental health problems can lead to improvements in estimates of prevalence, provision of services, effective intervention and outcome (National Audit Office, 2009b). Using evidence-based, standardised tools increases the reliability and validity of diagnoses (NICE, 2010).

The literature suggests that a significant proportion (around 30-40%) of specialist mental health service users with intellectual disability also have ASD (Emerson & Baines, 2010; Matson & Shoemaker, 2009). There is good evidence that those with and without ASD differ on a range of socio-demographic and clinical variables.

Adults with intellectual disability appear to be at higher risk of mental health problems than the general population (Cooper et al., 2007) as do adults with ASD (Hutton et al., 2008). There is evidence that adults with both intellectual disability and ASD are at further increased risk of problem behaviour, However, it is less clear whether there are differences in the prevalence and pattern of psychiatric disorder between those with and without ASD (Melville et al., 2008; Underwood et al., 2010).

In the UK, there are Government strategies in place to ensure that people with intellectual disability, ASD and mental health problems have improved access to assessment and services (Department of Health, 2001b; 2010b; 2011). However, the evidence base for service provision, specific interventions and the implementation of guidelines for people with intellectual disability and ASD is weak (NICE, 2011).

Early research reported generally poor life outcomes for adults with ASD (Howlin et al, 2004). There is evidence that those with intellectual disability and more severe ASD do less well in adult life (Cederlund et al., 2008; Marriage et al., 2009). Little is known about whether adults with intellectual disability and ASD who are receiving services for mental health problems have poorer social functioning compared to those with intellectual disability alone. Verbal ability, IQ, support characteristics and level of unmet formal support needs appear to affect the social functioning of people with ASD. However, the interaction between these factors is unclear.

More research on the mental health of adults with intellectual disability and ASD is needed. Understanding which service users appear to have poorer mental health, behaviour and social functioning than others despite receiving psychiatric treatment, and the extent to which having ASD is a contributing factor, should inform the development of more effective services and lead to improved outcomes.

Aims and objectives

The thesis aimed to find out whether:

- Specialist mental health service users with intellectual disability and ASD have a different clinical profile compared to those without ASD.
- Specialist mental health service users with intellectual disability and ASD have poorer mental health, behaviour and social functioning compared to those without ASD.

The objectives of the thesis were to:

- Explore whether the mental health needs of adults with intellectual disability and ASD are being adequately provided for by specialist mental health services for adults with intellectual disability.

- Determine whether there is any evidence (from a clinic-based population) to support the hypothesis that adults with intellectual disability and ASD have poorer mental health and social functioning compared to those without ASD.

To achieve the aims of the thesis, data were collected from a sample of specialist mental health service users who had intellectual disability with and without ASD using evidence-based, standardised methods. A combination of observation, informant interview and case note review were used to explore participants' characteristics, needs, service use, medication use, mental health, behaviour and social functioning. Crucially, the study was able to validate existing clinical diagnoses of ASD using gold standard diagnostic assessment.

In addition, a large survey of specialist mental health service users with intellectual disability was carried out using routinely collected clinical data. This study was designed to determine the extent to which results from participants in the main study were generalisable to the clinical population from which they were sampled.

The hypotheses for study were:

H1: Participants with intellectual disability and ASD will have a significantly greater number of needs than those without ASD (as measured by the CANDID[1]).

H2: Participants with intellectual disability and ASD will have significantly poorer health and social functioning than those without ASD (as measured by the HoNOS-LD).

H3: Participants with intellectual disability and ASD will have significantly poorer mental health than those without ASD (as measured by the DBC[2]).

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[1] Camberwell Assessment of Need for adults with Developmental & Intellectual Disability (Xenitidis et al., 2003)
[2] Developmental Behaviour Checklist for Adults (Mohr et al., 2004)

H4: Participants with intellectual disability and ASD will have significantly higher levels of problem behaviour than those without ASD.

H5: Participants with intellectual disability and ASD will have significantly poorer social functioning than those without ASD (as measured by a specially devised Social functioning scale).

H6: Participants with intellectual disability and ASD will have significantly higher levels of mental health service use than those without ASD (as measured by a Service Consumption Score).

H7: Participants with intellectual disability and ASD will have significantly higher levels of medication use than those without ASD.

H8: In addition to presence/absence of ASD, the mental health and social functioning of participants will be associated with unmet needs, level of service use and severity of intellectual disability.

The factors included in hypothesis eight were sourced from the literature review. However a range of other – potentially confounding – variables will also be explored. These include age, gender, ethnicity and type of residence.

Chapter 7: Introduction to the methodology

As previous chapters have described, research on the mental health of adults with intellectual disability and ASD is in its infancy. This is in part because this area was not previously recognised as important but also because of the challenges that face researchers when carrying out research with this complex service user group. The lack of earlier research makes designing studies difficult; there is a little evidence on which to base decisions about eligibility criteria, sample size, measures and analyses.

This chapter has two sections covering general methodological issues and the specific methods used in the research studies for the thesis. The first section looks at the range of considerations that should be taken into account when conducting research on the mental health of adults with intellectual disability and ASD. A number of these are relevant to health services research in general where as others are more specific to the participants in these studies. Study design, sources of data, recruitment issues and capacity to consent to take part in research are discussed.

The second section of the chapter describes the design of the research studies that form the thesis; including the participants and the clinical setting from which they are sampled. The specific eligibility criteria, procedures, methods of data collection, measures and analyses of each study are reported in Chapters 8 and 10.

Research on the mental health of adults with intellectual disability and ASD

Methodological issues such as diagnosis and assessment have been discussed in previous chapters and individual measures will be described later in chapters 8 and 9. There are a number of additional, practical challenges that face researchers when including participants with complex needs. People with intellectual disability and/or ASD vary greatly in terms of

their characteristics and also their ability to understand research, engage with others, make decisions and express their views.

Study design

The research studies were principally descriptive and designed to find out whether users of a specialist mental health service for adults with intellectual disability who have ASD are different from other service users with regards to their characteristics, mental health and social functioning. The aim was to provide a snap-shot of the lives of specialist mental health service users who have intellectual disability with and without ASD. As such, the studies employed observational, cross-sectional designs.

Data sources

Using a range of the best available sources and collecting data in a systematic way can increase confidence in the findings of research and reduce measurement bias (Prince, 2003). Information about participants can be assembled from existing records (e.g. medical notes), the person themselves or someone who knows them personally or in a professional capacity. The more structured and standardised the method of data collection the easier it is to compare individuals or groups of participants. Where available, it is preferable to use existing measures that have been methodically developed and tested (Prince, 2003).

Assessment tools may be participant-, informant- or observation-based. Participants can be asked to self-rate items on a questionnaire or they can be interviewed face-to-face by a researcher. However, this can be difficult for people with intellectual disability and/or ASD who may not be able to describe their feelings and experiences or may be unaware of the impact their behaviour has on others. They may also have difficulty understanding the questions being asked of them.

Many people with intellectual disability and/or ASD have limited verbal skills and some are unable to speak at all, though they may communicate using other means such as Makaton or pictorial aids. In these situations it seems appropriate to ask someone who knows the person well to act as their 'informant' and answer questions on their behalf. Though largely accepted in mental health research this method of data collection is not without its biases (Stewart, 2003).

An informant will often be asked to make judgements about an individual's thoughts, feelings and behaviour. In some situations informants may have reason to under or overplay a person's problems; perhaps if they feel they are being judged as a carer or if they hope to improve their access to services. Informants may be so accustomed to an individual's behaviour that they no longer consider it challenging or unusual.

This study sought to include individuals with intellectual disability of all abilities and collect data using standardised methods. It was important that each measure was suitable for all participants. Since there would be some participants who were unable to communicate with a researcher it was necessary to choose instruments that were designed to be administered using an informant. In the case of assessing whether participants did or did not have ASD, an observation based measure was chosen. This was because many informant-based tools rely on information about the person's early life and it was anticipated that many participants would not have an informant who had known them since childhood.

Accessing difficult to reach populations

Adults with intellectual disability and/or ASD are often socially excluded and may also have limited access to services. This can make it difficult to identify potential participants and also causes problems when approaching people to take part in research. Individuals may rely on other people to open and read their mail, be unable to access a telephone and have limited

direct contact with services. Their approachability is often dependent on the willingness of others to facilitate their involvement (such as family or paid support workers). This can introduce an element of sampling bias if individuals who agree to take part differ from those who refuse; e.g. they are more independent or have fewer problems. To reduce this bias a range of methods were used to approach participants including letters and face-to-face contact. Steps were taken to ensure that all correspondence and information given to participants was accessible for people with intellectual disability and ASD.

A further barrier for research is the relatively small proportion of the population that individuals with intellectual disability and ASD who have mental health needs represent. This has been estimated to be around 0.05% of the general population (see Chapter 3); impeding the ability of single site studies to recruit sufficient sample sizes. Having a small number of potential participants is likely to make random sampling unfeasible or even unnecessary since it will be more practical to approach and attempt to recruit as many people as possible from the sample population. Since little is known already about the mental health of adults with intellectual disability and ASD it makes sense to develop the evidence base from easily defined, clinic-based populations. This should make it easier to identify potential participants and assess their eligibility. It also means that researchers can work with service providers to approach and recruit participants.

Capacity and consent

Research on adults with intellectual disability and/or ASD that only included participants who have capacity to consent would be restricted to a relatively small proportion of the group it set out to study. The sample would not represent the range of individuals seen in service settings; introducing omission bias. It would not be reasonable to generalise the findings of studies that only included people with less severe intellectual disability. It was therefore decided that the

studies for the thesis would be designed to include participants who lack capacity to consent to take part.

The Mental Capacity Act (MCA) Mental Capacity Act (MCA), 2005, its accompanying Code of Practice (Department for Constitutional Affairs, 2007) and guidance from the British Medical Association (2007), Medical Research Council (2007) and Department of Health (2008) give clear definitions of capacity and the requirements for research that seeks to recruit participants who lack capacity.

A person is said to have capacity to give informed consent to take part in research if they are able to demonstrate that they can: 1) understand the information about the research and what taking part will involve, 2) retain that information and use it to make a decision about whether to take part and 3) convey their decision

Their consent is only valid if the person is acting voluntarily and has been provided with sufficient information to enable them to make a decision (Department of Health, 2001a).

A person's capacity to consent may vary from situation to situation and over time. Someone who lacks capacity to consent to complex medical treatment may be able to understand and decide whether to answer a short questionnaire for a research study. It should be assumed that a person has capacity to consent until it is otherwise indicated.

Individuals who lack capacity to consent for themselves can be included in a research study if a consultee agrees that they can take part (Medical Research Council, 2007). A consultee is someone who knows the participant well and is not connected to the research. In the first instance, a personal consultee should be sought (someone who is not paid to care for the participant – usually a relative, friend or advocate). If there are no persons able or willing to

act as a personal consultee then a nominated consultee can be approached. This can be a paid carer provided they are independent of the research. A consultee is provided with information about the study, they are asked to consider the wishes and interests of the person who lacks capacity and whether they would be content to take part or whether doing so might upset them (Department of Health, 2008).

Summary of methodological issues

The issues described in this section contribute to the well-established difficulties encountered when recruiting participants with intellectual/developmental disability into research projects (Martin et al., 2005; Oliver et al., 2002). Chapters 2 to 6 demonstrated the relative lack of research on the mental health and service use of adults with intellectual disability/ASD and the likely reasons for this. Other challenges to the development of the evidence base include the complexity of services and delivery of interventions for this group and unwillingness among providers to take part in research or evaluate their services (Oliver et al., 2002).

Introduction to the research components of the thesis

Design

The thesis is based on cross-sectional data from a clinic-based population.

Participants

Data were collected from users of a specialist mental health service for adults with intellectual disability.

Two groups of participants were compared:

1) Adults with intellectual disability who have ASD (ASD)
2) Adults with intellectual disability who do not have ASD (no ASD)

A third set of participants was identified: adults with intellectual disability who have traits, features or behaviours consistent with ASD but no formal clinical diagnosis.

In some cases this group's ASD traits had been identified prior to the study and were mentioned in their mental health record. In other cases the presence of ASD traits only became apparent during the assessments carried out for the study. Data from these participants were analysed separately (see Chapter 11).

The two studies for the thesis were:

1) An in-depth comparison of participants with and without ASD using standardised measures to collect data from a sample of service users.

2) A supplementary comparison of those with and without a clinical diagnosis of ASD using anonymised data from an entire clinic population.

Clinical setting

All participants were users of a specialist, multi-disciplinary, community-based mental health service for adults with intellectual disability. This Mental Health in Intellectual Disability (MHID) service is provided by the South London and Maudsley NHS Foundation Trust (SLaM) (Chaplin et al., 2010a). SLaM provides mainstream and specialist mental health services to the London boroughs of Croydon, Lambeth, Lewisham and Southwark.

This area has a population of just over 1 million people (Stewart et al., 2009). Lambeth, Lewisham and Southwark are among the ten most deprived boroughs in London, while Croydon is ranked 20th (Department for Communities & Local Government, 2007). Lambeth, Lewisham and Southwark have higher numbers of people from Afro-Caribbean backgrounds

than the national average (around 24% compared with 3% for the England and 11% for London) where as Croydon is more in line with London-wide statistics (13%) (Office for National Statistics, 2001).

The MHID service is made up of specialist community psychiatric nurses (CPNs who have received mental health in intellectual disability training) and intellectual disability psychiatrists. The service provides community psychiatric assessment, intervention and follow-up. This can include referral to local Learning Disability Partnerships who employ specialist psychologists, behavioural support workers, occupational therapists and speech & language therapists.

Services are provided through psychiatry outpatient appointments/home visits and outreach nursing (Chaplin et al., 2006). Medication is prescribed to service users via their general practitioners (GPs). Service users who require an enhanced level of input are placed on the Care Programme Approach (CPA).

The MHID service accepts referrals from primary care, social services/community services for adults with intellectual disability and generic adult mental health services (Bouras et al., 2003). When a referral is received, the eligibility of the individual is considered and if appropriate they are invited for a multi-disciplinary assessment with an intellectual disability psychiatrist and a CPN (see eligibility criteria below). At the initial appointment, eligibility for the service and any existing diagnoses are reassessed. Information on the person's history and current mental state is gathered using a structured assessment package (Chaplin et al., 2006). This is used as the basis for diagnostic formulation according to ICD-10 criteria (WHO, 1992). A broad range of elements of a service users' presentation are assessed including:

- Presence and severity of intellectual disability
- Presence of a psychiatric disorder or challenging behaviour
- Presence of any additional disorders including ASD
- Presence of any physical/sensory disabilities or health problems

This information is recorded in the service user's mental health record and in follow-up letters to the referrer and other relevant parties including the person's GP.

Eligibility criteria

Individuals are eligible for the MHID service if they:

1) are over 18 years of age,

2) are resident in Croydon, Lambeth, Lewisham or Southwark,

3) have a diagnosis of intellectual disability (defined as IQ below 70 and significant social impairment; both present from childhood)

and 4) have an additional mental health problem and/or significant risk behaviour (defined as any mental disorder included in any classification system or challenging behaviour that requires psychiatric mental health intervention).

The presence of ASD in addition to intellectual disability is not sufficient to meet the fourth inclusion criteria; adults with intellectual disability and ASD must have an additional mental health problem or challenging behaviour to be eligible for the service. Adults with ASD who have mental health problems or challenging behaviour are only eligible if they have intellectual disability.

Following the initial assessment, patients are accepted on to the service's caseload or discharged back to their GP. A care plan is devised for people accepted into the service that sets out the decisions made about their care. This includes whether they will be placed on CPA, how often they will be seen and by whom, whether they will be referred to any other services and what treatment they will receive.

Service users are seen by appointment at weekly outpatient clinics or where necessary at home. MHID does not operate an emergency service or out-of-hours appointments. Service users not on CPA are offered appointments with an intellectual disability psychiatrist or CPN from a once yearly review up to around every 3 months or more often if required. Those who are on CPA have contact with a CPN by outpatient or home visit once every two weeks. Many service users also see their CPN regularly for administration of depot medication. There is no limit on the length of time that an individual can remain on the service's caseload.

Clinical data

All SLaM service users' mental health records are managed using the electronic Patient Journey System (ePJS). This is a computerised online application which replaced paper records in 2006 (Stewart et al., 2009). Information is recorded and stored in defined fields, entered as text or uploaded as attachments. Paper records from before 2006 have been digitally archived and added to service users' ePJS files.

All contacts, events concerning service users, referrals, discharges, correspondence regarding service users and the results of clinical assessments are recorded on ePJS as well as socio-demographic and clinical information (including diagnoses according to ICD-10 categories, current medication and care plans).

It is MHID policy to routinely measure clinical outcome using the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD; Roy et al., 2002). The HoNOS-LD should be administered at initial assessment, before a review (CPA/6 month review or crisis review) or on discharge from the service (Chaplin et al., 2006). Each assessment is recorded on ePJS.

Summary of the research components for the thesis

The MHID service is a good example of a well-developed specialist mental health service for adults with intellectual disability (Chaplin et al., 2010a). It may not be typical of services within the UK but it offers a number of advantages for research:

- Well-defined eligibility criteria.
- Access to a large number of service users in a compact geographical area.
- Multi-disciplinary assessment by specialist clinicians.
- The use of standardised diagnostic criteria (ICD-10; WHO, 1992).
- Clear care pathways and protocols (see www.estiacentre.org/workingpapers.html)
- The use of standardised outcome assessment (HoNOS-LD; Roy et al., 2002).
- Standardised and electronic recording of clinical mental health records.

Chapter 8: Methodology

This chapter describes the method of the main study for the thesis. The study aimed to collect a broad range of data on participants' characteristics, needs, service use, mental health, behaviour and social functioning. A standardised diagnostic assessment was used to confirm whether or not participants had ASD.

Participants

The study included individuals who were accepted service users on the Mental Health in Intellectual Disability (MHID) service caseload between January 2009 and December 2010 (see chapter 7 for the service's eligibility criteria).

Sampling

The mental health records of service users were reviewed to identify a) those with a documented clinical diagnosis of ASD, b) those described as having autistic traits/features/behaviours and c) those without any mention of ASD.

The study focussed on Lambeth, Lewisham and Southwark (LLS) service users and did not initially seek to recruit participants from Croydon. This was because at the time of the initial screen for service users for with ASD, the mental health records for Croydon service users were not available on the electronic Patient Journey System (ePJS).

It was thought that there would be sufficient numbers of participants on the LLS caseloads (N≈500) to recruit the planned sample size of 50 participants with ASD and 50 without ASD. All LLS service users with a documented clinical diagnosis of ASD who were eligible for the study were approached to take part.

Eligibility criteria

The inclusion criteria for the study were that a participant was:

1) an accepted service user on the MHID caseload between January 2009 and December 2010 (see chapter 8 for the service's eligibility criteria)

and 2) willing to provide informed consent (or a consultee was willing to assent if a participant lacked capacity).

The exclusion criteria for the study were that a participant was:

1) subsequent to being accepted, deemed ineligible to receive MHID services and was due to be discharged,
2) yet to be assessed or had no information in their mental health record to determine whether they had a clinical diagnosis of ASD,
3) currently an inpatient in hospital or resident at a secure unit,
4) currently placed 'out of area' (i.e. in a residential or treatment facility outside of Croydon, Lambeth, Lewisham or Southwark),

or 5) considered by their care co-ordinator to be unsuitable for the research project.

The study then employed a systematic process of confirming participants' eligibility for each group with and without ASD.

<u>Eligibility for ASD group</u>

The inclusion criteria for the ASD group were that a participant:

1) had a clinical diagnosis of ASD documented in their mental health record.

and 2) exceeded the threshold for ASD on the Autism Diagnostic Observation Schedule (ADOS) or there was evidence they met ICD-10 criteria for ASD according to a review by an intellectual disability psychiatrist (see Assessment of ASD, page 113).

Eligibility for group without ASD

The inclusion criteria for the group without ASD were that a participant:

1) had no mention of ASD, autistic traits, behaviours or features in their mental health record

and 2) scored below the threshold for ASD on the ADOS or there was evidence they did not met ICD-10 criteria for ASD according to a review by an intellectual disability psychiatrist

Ethical approval

The study was granted ethical approval by the St Thomas' Research Ethics Committee in June 2008 (reference: 08/H0802/52). The study was also approved by the Institute of Psychiatry Research and Development Office (reference: R&D2008/024). Substantial amendments to include a wider range of measures and recruit participants from a larger sample base were granted in November 2008 and November 2009 respectively (see Appendix IV).

Capacity and consent

It was anticipated that many participants would lack capacity to give informed consent because of their intellectual disability, ASD or mental health problem. The study was therefore designed to include participants who were unable to consent to take part in research.

The study first sought the opinion of individuals' care coordinators and carers on whether the person had capacity to decide whether to take part in the study. This was followed up by the completion of a capacity checklist by an experienced researcher when they met the participant (see Appendix V). If a participant was unable to meet the criteria for capacity to consent, a personal consultee (unpaid carer, family member or friend) was sought. A nominated consultee was sought in cases where an individual had no family, unpaid carer or advocate

who was willing to act as a consultee. Consultees were asked to discuss the study with the service user and/or any other relevant people. If they agreed that the person could take part they were asked to sign an assent form.

Procedure

Recruitment began in January 2009. A list of service users with a clinical diagnosis of ASD was obtained from a database used in previous research (Bouras et al., 2003). The ePJS was searched to find those on the current caseload and obtain their contact details. From November 2009 the sample was extended to include participants on the current caseload who had not taken part in the previous research. The list of people on the caseloads was updated throughout 2010 to add any new service users.

Identification of service users with and without a clinical diagnosis of ASD

The ePJS was used to screen the mental health records of potential participants for the study. The researcher looked for any mention of ASD, 'autistic traits' 'autistic behaviours' or 'autistic features' in the diagnosis section of ePJS, in correspondence to the service user's GP, in care plans or if, these were not available, in any document written by a health or social service professional involved in the person's care.

Following this screen, service users were put into three groups. Service users in groups one and two were considered for inclusion in the study.

1) Individuals with a clinical diagnosis of ASD documented in their mental health record.
2) Individuals for whom there was no mention of ASD, autistic traits, behaviour or features in their mental health record.
3) Individuals with a provisional diagnosis of ASD that was yet to be assessed and service users who were said to have autistic traits, behaviours or features not reaching the criteria for a diagnosis of ASD or not formally assessed.

Recruitment

Service users were approached by post or in person when they attended an outpatient appointment. Potential participants were given a letter from a consultant psychiatrist from the MHID service. Also enclosed were a Service User Participant Information Sheet, reply form and stamped addressed envelope. All correspondence and information sheets were designed to be accessible for people with intellectual disability. They were developed in consultation with Steve Hardy (Estia Centre, King's College London) who is a specialist in education and training on the mental health of adults with intellectual disability.

Service users who were interested in taking part in the study were asked to contact the researcher team by telephone, email or using a reply form given to them with the study information. A researcher arranged to meet the participant and their informant to carry out a capacity assessment and where appropriate the informant interview and ASD assessment for the study.

Informed consent was obtained from all participants who had capacity and agreed to take part (see Appendix V for the service user letters, participant information sheet and consent/assent form). Where a participant did not demonstrate capacity to consent, a consultee (a person well-known to the service user who was not connected to the research programme) was appointed to decide and give assent on their behalf.

Matching procedure

For every individual with ASD attempts were made to recruit a matching participant without ASD. Matches were made on a case-by-case basis according the priorities and categories listed below.

Primary matching criteria in order of priority:

Severity of intellectual disability	Exact match (mild/moderate/severe)
Gender	Exact match (male/female)
Age	As close as possible (preferably within 5 years but up to 10 years or beyond if necessary)

If several matches were available additional criteria were employed to choose which potential participant would be approached.

The secondary matching criteria were:

Psychiatric disorder	Presence/absence of a diagnosis (where present; specific disorder or type of disorder[1])
Type of residence	Living independently/with family/in a residential placement
Ethnic group	Afro-Caribbean//white/other or unclear

When a suitable participant with no clinical diagnosis of ASD was recruited to the study they were assessed using the eligibility criteria described above. If a participant did not meet the study criteria for 'no ASD' they were excluded and a replacement who was the next best match was approached.

Selection, recruitment and assessment of those without a clinical diagnosis of ASD continued using this process until it was necessary to approach participants who were not good matches to those in the ASD group. This was because there were no suitable matching candidates among the remaining sample of potential participants. When there were no further

[1] psychotic or bipolar disorder/depression or anxiety disorder/dementia/other disorders

participants without a clinical diagnosis of ASD left to approach from the Lambeth, Lewisham and Southwark caseloads, the sample was broadened to include service users from Croydon.

Measures

The selection of measures used in the study took into account whether there was an evidence-base or precedent for the tool's use in research on adults with intellectual disability. The instruments employed were selected on the basis that they:

- Were suitable for use with adults
- Were suitable for all severities of intellectual disability
- Were designed for or could be used for interviews with lay informants who knew the participant and their current behaviour well but did not necessarily have information about their earlier life or developmental history
- Could be completed by a trained and experienced researcher
- When used together would not take longer than three hours to administer

The measures used in the study are listed below. The method of data collection for each measure is denoted by the following superscripts: 1) Informant interview, 2) Case note review and 3) Observational assessment. See Data collection below for more details on these methods.

See Appendix V for copies of non-standardised measures: service user profile form, informant profile form and review of participants' mental health record.

Socio-demographic and clinical characteristics

Socio-demographic characteristics:	Service user profile form[1] Mental health record (ePJS)[2]
Intellectual disability diagnosis:	ICD-10 diagnosis according to ePJS record[2]
ASD assessment:	ICD-10 diagnosis according to ePJS record[2] Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989)[3] Social Communication Questionnaire (SCQ; Berument et al., 1999)[1] ICD-10 diagnosis according to review by an intellectual disability psychiatrist[1,2]

Needs, service use and interventions

Needs:	CANDID (Xenitidis et al., 2000)[1] Client Service Receipt Inventory (CSRI; Beecham & Knapp, 1992) [1]
Mental health service use and medication:	Mental health record (ePJS)[2]
Primary health care, other healthcare, social service and day centre use:	CSRI[1]

Mental health and problem behaviour

Psychiatric disorder:	Mental health record (ePJS)[2]
Health and social functioning:	HoNOS-LD (Roy et al, 2002)[1]
Mental health:	Developmental Behaviour Checklist for Adults (DBC; Mohr et al., 2005)[1]
Problem behaviours:	DBC[1] HoNOS-LD[1]

Social functioning

Communication, community life, employment, independence, social interaction:	HoNOS-LD CSRI[1]
Social functioning:	Social functioning scale for adults with developmental disability[1]

Assessment of intellectual disability

The study relied on the clinical assessment of participants' severity of intellectual disability by specialist intellectual disability psychiatrists according to ICD-10 criteria. Anyone referring an individual to the MHID service must provide evidence that the person has an IQ below 70 before they will be considered for an assessment (Chaplin et al., 2006). Where there was evidence from a participants' mental health record that their level of functioning had been assessed using a standardised psychometric test, the results were cross-checked with their clinical diagnosis.

Assessment of ASD

Initial selection and allocation to study group according to presence or absence of ASD was made on the basis of routine clinical assessment according to ICD-10 criteria. This was sourced from participants' mental health records and recorded during the recruitment process (see Procedure above).

Diagnostic ASD assessment

Confirmation of the presence or absence of ASD was established using the ADOS (Lord et al., 1989). Four methods of diagnostic assessment were considered: ADI-R, ADOS, DISCO and 3Di. The ADOS was chosen as it could be used for all participants; not just those with an

informant who knew their developmental history. It is also the only instrument that involves direct contact with the person being assessed rather than reliance on an informant.

As reported in Chapter 2, the ADOS is considered one of the 'gold standard' methods of carrying out a diagnostic ASD assessment and is recommend by clinical guidelines for adults with ASD (NICE, 2012). It comprises four modules; one of which is chosen based on the participant's verbal ability. An ADOS assessment takes around 45 minutes to complete. A trained administrator attempts to engage the participant in a series of 'presses' and rates their social communication, interaction and behaviour (Lord et al., 1989). The presses range from response to name (module 1) to discussing emotions (module 4). The assessor also uses the presses to observe the person's use of eye contact or gestures, the quality and frequency of their social responses and whether they initiate interaction. All assessors using the ADOS for research purposes must have completed an official training course.

Under the following circumstances an ADOS assessment was not carried out:

1) the participant refused,

2) the participant's consultee refused,

3) the participant's level of functioning was below that at which an ADOS can be carried out (e.g. equivalent to under 18 months old)

or 4) the participant had a physical disability or sensory impairment such that it was not possible for them to complete the tasks that form the ADOS assessment.

Additional ASD assessment

It was anticipated that it would not be possible to assess all participants using the ADOS therefore an ASD assessment was included in the informant interview. Tools identified in the

literature review that were suitable for adults with intellectual disability were considered: the ASDASQ, ASD-DA, PDD-MRS and SCQ (see Chapter 2). The SCQ was chosen as it is suitable for all levels of functioning and was designed to be completed by a lay informant rather than an observing clinician.

The SCQ was developed from the Autism Screening Questionnaire as a brief ASD screening tool for children (Berument et al., 1999; Rutter et al., 2003). It has two versions; the lifetime form covers the individual's developmental history and has content parallel to the ADI-R, where as the current form looks at behaviour over the last three months. The SCQ is designed to be completed by a parent or carer. It has one item on whether the individual is able to talk in short phrases then 33 (if the person is non-verbal) or 39 items (if the person is verbal) with yes/no responses, which depending on the direction of the question, score either 0 or 1. The total SCQ score is calculated by adding the total number of 1s scored.

Review of participants without an ADOS result

A consultant intellectual disability psychiatrist reviewed participants who could not complete an ADOS assessment. A file was compiled for each person comprising the completed schedules from the informant interview and case note review (including the SCQ). Additional information was sourced from ePJS; such as all available details of the participant's clinical diagnosis of ASD (for those in the ASD group), outpatient follow-up letters to their GP and any other relevant reports or assessments.

ICD-10 Diagnostic Criteria for Research (WHO, 1993) were used to confirm that:

1. participants in the ASD group met the criteria for ASD
2. participants in the 'no ASD' group did not meet the criteria for ASD

Assessment of Needs

The Camberwell Assessment of Need was developed to measure the needs of people with severe mental illness (Slade et al., 1999). Four variants have been developed: CANDID for adults with developmental and intellectual disability; CANE for the elderly; CANFOR for forensic settings and CAN-M for mothers. Each assessment has three versions: clinical, research and short appraisal schedule. The CANDID was designed for people with intellectual disability who have mental health problems. It is designed to provide a multi-perspective assessment of need from the individual themselves, a member of staff and an informal carer (Xenitidis et al., 2003).

The CANDID covers 25 areas of need, each are rated according to whether in the last four weeks there was: no need (no serious problem in this area and no help given); met need (appropriate help being given for a particular problem) or unmet need (a serious problem and no help currently being given or a serious problem despite help being given). For each perspective three scores are calculated: 1) total number of met needs, 2) total number of unmet needs and 3) total number of needs (total of 1 and 2).

The CANDID has been used to measure the needs of adults mental health service users with intellectual disability (Hall et al., 2006; Martin et al., 2005). It has also been used with older people with intellectual disability in the UK (Strydom et al., 2005) and Ireland (McCausland et al., 2010). The CANDID has been found to have good reliability and validity (Xenitidis, 2000).

Service use

Data on service use were collected from mental health records and during an informant interview using the Client Service Receipt Inventory (CSRI). All contacts with health or

social services recorded on ePJS were extracted for the 12 month period prior to the informant interview. These included outpatient appointments, home visits and face-to-face meetings with the participant and/or their carers. Data were recorded on the profession of the clinician and the service they worked for. Visits to non-mental health services (e.g. GP or hospital appointment) were also recorded.

Client Service Receipt Inventory (CSRI)

The CSRI was developed as a method of collecting data on service use and related characteristics of people with mental disorders (Chisholm et al., 2000). Although designed to be used for mainstream health and social care services the CSRI is adaptable for specific user groups. The questionnaire is completed with the participant or an informant and covers socio-demographics, usual living situation, employment and income, service receipt and medication profile.

The CSRI is widely used to evaluate economic costs of service use in both research and clinical settings (Beecham & Knapp, 2001). It has been used in several studies on the service consumption of adults with intellectual disability or ASD (Felce et al., 2008; Hallam et al., 2006; Jarbrink & Knapp, 2001; Knapp et al., 2005; Knapp et al., 2009). Studies have found good agreement between data collected on number of visits to health professionals using the CSRI and case records (Patel et al., 2005).

Service Consumption Score (SCS)

An adapted version of service consumption score (SCS) was used to look at the relative mental health service use of those with and without ASD (Lavik, 1983). Similar methods have been used before to investigate mental health service use among adults with intellectual disability (Driessen et al., 1997; Spiller et al., 2007).

It was anticipated that contact with mental health services would vary widely and involve combinations of different clinicians, outpatient appointments, home visits, meetings in the community and inpatient stays. Because of this complexity, a crude measure of service use was adopted where each contact was assigned one 'point' regardless of where it occurred or with whom. SCS included each contact with a MHID psychiatrist, MHID CPN, psychologist, behaviour support worker, mainstream mental health service and psychiatric inpatient stays.

Mental health and behaviour problems

The study explored existing clinical diagnoses of psychiatric disorder as well as standardised measures of mental health and behavioural symptoms.

Psychiatric diagnoses

The study relied on routine clinical assessment of whether participants had an additional psychiatric disorder. This was carried out by specialist intellectual disability psychiatrists according to ICD-10 criteria. Currently, there is no 'gold standard' diagnostic assessment of mental health for adults with intellectual disability (see Chapter 2). The most robust diagnoses are likely to be those made through *"Comprehensive, specialist psychiatric assessment using standardised diagnostic criteria from a longitudinal perspective incorporating life events, past abuse and other medical issues."* (Bradley et al., In press).

The analyses focussed on the primary disorder for which the participant was receiving mental health services regardless of whether this was in remission at the time of the review. If a participant had not received a diagnosis of any additional psychiatric disorder it was assumed they were receiving specialist mental health services for impairment of behaviour.

Health of the Nation Outcome Scales for people with Learning Disabilities

The Health of the Nation Outcome Scales (HoNOS) are a set of measures developed by the Royal College of Psychiatrists. They were designed for the Department of Health to measure the health and social functioning of people with severe mental illness (Royal College of Psychiatrists, 2006). A number of adapted scales for specific groups have been derived including the HoNOS-LD for people with learning disability (Roy et al., 2002).

The HoNOS-LD has 22 items covering a range of domains. Each item is rated from 0 (no problem) to 4 (very severe problem). Items are rated at the current level achieved with existing support. Thus a person who is unable to wash or dress themselves may still score 0 on level of self-care if their appearance and personal hygiene are well maintained albeit with help from others. The questionnaire is designed to be completed by a trained administrator in an interview with the individual themselves or an informant. Ratings are based on the last four weeks. A total score is calculated by adding the scores of all 22 items. A higher total score on the HoNOS-LD indicates lower health and social functioning (Roy et al., 2002).

The HoNOS is used widely in clinical practice and research (Pirkis et al., 2005) and forms the basis of the clustering and outcome measurement for Payment by Results (Department of Health, 2010d). The HoNOS-LD is used by many mental health in intellectual disability services and as an outcome measure in research (Baker & Daynes, 2010; Hillier et al., 2010; Tenneij et al., 2009; Sakdalan et al., 2010).

The HoNOS-LD is a broad measure; it contains some items that are likely to change over time and others which tend to remain more stable (Roy et al., 2002). The magnitude of change in mean total score is not thought to be associated with severity of intellectual disability (Roy et al., 2002). The HoNOS-LD has been reported to have good reliability and validity (Tenneij et al., 2009). It has been recommended as a well-validated measure which should be used by

research studies to evaluate outcomes for adults with intellectual disability who have mental health problems (Prakash et al., 2007). There is no evidence on whether the HoNOS-LD has different properties when used with adults with intellectual disability and ASD.

Two studies have carried out factor analyses of the HoNOS-LD. The first was a study of 155 community intellectual disability service users that identified four factors (Skelly & D'Antonio, 2008). These were: communicative-cognitive competence; behaviour disturbance incorporating relationship breakdown; loss of adaptive behaviour incorporating acute physical illness and internal dysregulation. These factors accounted for 48% of the variance among responses with each factor explaining 9-15% of the variance. No further psychometric properties were provided.

A more recent study sourced HoNOS-LD data from 2032 mental health service users (Tsakanikos et al., In preparation). In this analysis, three subscales were identified: Neuro-cognitive functioning, Mental health/behaviour and Health/social functioning. These factors accounted for 43% of the variance with each factor explaining 7-26% of the variance. The internal consistency of these factors according to Cronbach's alpha ranged from 0.76 to 0.8 (see Appendix I).

The HoNOS-LD was designed for individuals with mental health problems rather than as a generic outcome tool for adults with intellectual disability. Given this and the greater number of participants on which the analysis was based, the factors identified by Tsakanikos et al. (In preparation) were used for the clinical study data.

Six items within the HONOS-LD focus on problem behaviour: problems directed towards others, self-injury, behaviour destructive to property, problems with personal behaviours, rocking, stereotyped & ritualistic behaviour and others. These items were used to form a HoNOS-LD problem behaviour subscale.

Developmental Behaviour Checklist

The review of assessment tools carried out for Chapter 2 found that there are three types of measure: purely psychiatric, purely behavioural and a combination of mental health and behaviour problems (Unwin & Deb, 2008). The Developmental Behaviour Checklist for adults (DBC) was chosen to measure participants' overall psychopathology (Einfeld & Tonge, 2002). This was based on the strength of the evidence for its psychometric properties and its suitability for all ranges of intellectual disability severities (Mohr et al., 2004). Of the mental health assessments reviewed in Chapter 2, the DBC was the only measure that provided a total score of psychopathology. The PAS-ADD, PIMRA and DASH are screening and diagnostic tools that provide subscale scores and dichotomous outcomes of disorder/no disorder rather than a continuous measure of current symptomatology.

The DBC contains a number of behavioural items in addition to mental health symptoms. Many of these are identical or similar to items in other behavioural measures. For example, nearly all of the 58 ABC items are included in the DBC (Mohr et al., 2005). Total scores on these two scales are highly correlated (ibid).

The DBC-A has 108 behaviours or problems, listed alphabetically, and one final item on whether the person has problems with feelings or behaviour, in addition to problems with their development. Each items is rated "0" if it has not been true/has not occurred in the last six months, "1" if it has been somewhat true or sometimes occurs and "2" if it is very true or often occurs.

The authors have suggested three cut-off scores of the Total Problem Behaviour Score (TPBS) on the DBC-A that indicate psychiatric 'caseness' (Mohr et al., 2004). A threshold of 96 was found to be 100% specific compared with clinical judgement. Using a cut-off of 51;

the scale had a specificity of 50% and sensitivity of 87%. At a cut-off of 31 the specificity was 6% and sensitivity was 100%.

Six DBC-A subscales have been identified by factor analysis: Disruptive, Self-absorbed, Communication disturbance, Anxiety/anti-social, Social relating and Depressive. There is no information on what constitutes a clinically significant difference in DBC-A scores. The manual of the 96-item DBC-P suggests that a change of 17 points or more on the TPBS can be attributed to an actual change in behaviour (Einfeld & Tonge, 2002). Translated according to the number of items in the DBC-A this would suggest that a difference of 19 points is clinically significant.

DBC mental health and problem behaviour subscales

It was recognised that the DBC is a broad measure that includes both mental health and behavioural symptoms as well as a number of ASD characteristics. As such, efforts were made to separate out the different types of items. A researcher and consultant intellectual disability psychiatrist reviewed the DBC items to determine which category each belonged to (mental health or behaviour). To aid this review, the items were compared with behaviours and symptoms included in other scales.

Comparative mental health measures: depression, psychosis and anxiety subscales of the DBC for children, Mini PAS-ADD and DASH-II mental health subscales (Anxiety, Depression, Mania and Psychotic disorder).

Comparative problem behaviour measures: Aberrant Behaviour Checklist, Challenging Behaviour Checklist, DAS-B, Behaviour Problem Inventory and DASH-II behaviour subscales (stereotypes/tics, self-injurious behaviours and impulse control/miscellaneous behaviour problems).

Following this review, the DBC items were split into two categories – 1) Mental health problems (34 items) and 2) Behaviour problems (72 items) (see Appendix VI).

Social functioning scale for adults with developmental disability

A scale of social functioning for adults with developmental disability was specially devised for the study. Items included in the scale were derived from the informant interview including the CSRI and HoNOS-LD. The scale was developed following a review of the measures described in Chapter 4, particularly those used by Howlin (2000; 2004) and Lotter (1978) (see Appendix V).

These measures used information extracted from other measures rather than direct collection of data. They have been widely used and were developed specifically to explore adult outcome for people with ASD. However they were not designed for people with intellectual disability and many of the items relate to functioning in such a way that individuals with more severe intellectual disability will always appear to have poor social functioning (Levy & Perry, 2011) .

None of the existing measures appeared suitable for comparing specialist mental health service users who have intellectual disability with and without ASD. Therefore a new measure of social functioning was developed with items that could be extracted from the tools used by the study. The criteria for the item ratings of the scale were carefully chosen based on the principle it should be achievable for an individual with any severity of intellectual disability to have a rating of excellent social functioning.

An expert with intellectual disability advised on the development of the scale. Wendy Perez is a self-advocate who runs her own company providing consultation on person-centre planning, improving accessibility and citizenship for people with intellectual disability (Holman, 2005).

She has advised on a number of service development and policy documents including Valuing People and Better Services for People with ASD (Department of Health, 2006a; Dowling et al, 2006; Hall et al, 2008; Hollins & Perez, 2000: Royal College of General Practitioners, 2010).

The Social functioning scale covers five domains: structured activity, independence, social life, community life and communication. Each domain has four levels. Table 8.1 and Table 8.2 (overleaf) show how the items are scored and how they contribute to an overall social functioning rating of Excellent, Good, Fair, Poor or Very Poor.

Table 8.1 Items included in the social functioning scale for adults with developmental disability

Sub-scale	Score	
Structured activity	3	In paid, supported or voluntary work, at college or in training for ≥0.6FTE*
	2	In paid, supported or voluntary work, at college or in training for ≥0.2 FTE but <0.6
	1	FTE or other structured activities ≥0.6 FTE
	0	In paid, supported or voluntary work, at college or in training for <0.2 FTE or other structured activities <0.6 FTE
		Not engaging in any structured activity outside of the home
Independence	3	Lives independently and is able to go out unsupervised
	2	Does not live independently but is able to go out unsupervised
	1	Unable to go out unless supervised
	0	Unable to go out regularly
Social interaction	3	Regularly sees friends and does not feel lonely
	2	Has friends but doesn't see them regularly or regularly sees friends but frequently
	1	feels lonely or isolated
	0	Has no particular friends but does not feel lonely or isolated
		Has no friends and feels lonely or isolated or has no friends and has minimal social interaction
Community life	3	Regularly accesses a range of amenities in the community
	2	Limited access to a range of amenities in the community
	1	Access to only one type of amenity in the community
	0	Never accesses any amenities in the community
Communication	3	No communication needs
	2	Some communication problems but able to needs to familiar people
	1	Difficulties expressing needs but able to understand other people
	0	No verbal or non-verbal communication and unable to understand other people

* Full time equivalent=35 hours per week

Table 8.2: Scoring of the social functioning scale for adults with developmental disability

Rationale for score	**Score**	**Level of social functioning**
Excellent on at least three items and no rating of poor	13-15	Excellent
Average score at least equivalent to good	10-12	Good
Average score more than adequate but less than good	6-9	Fair
Average scores less than or equivalent to adequate	3-5	Poor
Poor on three or more items and no rating of excellent	0-2	Very poor

Data collection

The data were collected in three phases: an interview with an informant, observational ADOS assessment and a case note review of participants' mental health records. On recruitment to the study each participant was assigned a unique identification number (study ID). Material containing information about participants (included the data collection schedules) was kept anonymous and separate from their contact details or anything that would allow them to be identified.

Informant interviews

Most of the data were collected during face-to-face interviews with informants. Participants (or where appropriate their carers) were asked to nominate the person who knew them best. This was usually a family member - when the participant lived with family; a keyworker or support worker - when the participant lived in a residential placement; or a community keyworker or support worker - when the person lived independently. At the request of the participant, their informant could also be a close friend or a health/social care professional who knew them well (e.g. their community psychiatric nurse).

Eligibility criteria for informants were that they had known the participant for at least three months and had contact with them at least once a fortnight. Participants were given the opportunity to attend the informant interview if they wished to. Informant interviews usually took place at the participant's home or the York clinic (Guy's Hospital) but could be carried out elsewhere at the request of the participant or the informant. All informants were given an information sheet and asked to sign a consent form. In some cases the informant was the same person that had acted as a consultee and given assent for the participant to be included in the research.

The following measures were administered at the informant interviews: service user profile, informant profile, CANDID, CSRI, DBC, HoNOS-LD and SCQ. The informant interviews were carried out by an experienced researcher between January 2009 and March 2011. The researcher received training on administering the informant interview measures from a consultant intellectual disability psychiatrist.

Observational ASD assessment

All participants were asked to attend an ADOS assessment. Where possible this took place at the York clinic, Guy's Hospital. In some cases the assessment took place at the participant's usual outpatient clinic. Where the person was unable to travel to any of these locations, the assessment was carried out in a suitable place at their home. Selection of the appropriate ADOS module was based on information provided at the informant interview. Modules 1 and 2 were carried out with a carer present if appropriate, modules 3 and 4 were carried out with the participant alone unless they specifically asked for a carer to be present. With the participant's consent (or where appropriate consultee's assent) the ADOS assessments were video recorded.

The ADOS assessments were carried out by five examiners between November 2009 and April 2011. All had completed official ADOS training including post-course requirements. One of the assessors was a researcher, one was a consultant intellectual disability psychiatrist, two were senior trainee intellectual disability psychiatrists and one was an assistant psychologist. All assessors had experience of working and carrying out research with adults with intellectual disability and/or ASD.

<u>Reliability and consensus coding</u>

The ADOS assessors met to view and code video recordings of the assessments. At these meetings a consensus coding and ADOS diagnosis (ASD or no ASD) was achieved.

Agreement (Cohen's kappa) between the original ADOS diagnosis and the consensus diagnosis was calculated and used as a measure of inter-rater reliability. It was not possible for all assessments to be recorded or all recordings to be consensus coded. Priority for consensus coding was given to assessments that indicated a differential diagnosis to the participant's clinical status for presence/absence of ASD.

Case note review

The ePJS was used to carry out a retrospective review of each participant's mental health records. Data were collected using a specially developed schedule (see Appendix V). The case note reviews were the source of all clinical and some demographic data on participants (i.e. age, severity of intellectual disability, psychiatric diagnoses, length of MHID service use, CPA status and medication). They were also used to measure participants' use of health and social care services in the 12 months prior to the informant interview.

The primary source of clinical data for the case note review were follow-up letters to participants' general practitioners (which include a section listing ICD Axis I, II and III diagnoses). Information given in most recent items of correspondence was cross-checked with previous correspondence and diagnosis data to ensure it was consistent across sources. The case note review of each participant covered the same 12 month period as their informant interview.

Data entry

Data from the informant interviews, ADOS assessments and case note reviews were entered into SPSS by an experienced researcher and two MSc students. All data entered by the students were double checked by the researcher.

Analysis

Prior to the comparison of the groups with and without ASD, exploratory data analyses were carried out to assess the quality of the data and measures. Distribution, missing observations and outliers were investigated. For each linear regression analysis a histogram of the standardised residuals was examined to check that the data were normally distributed. Participants who had outlying standardised residuals were removed from the analysis to improve the normality of the data.

Descriptive analyses and hypotheses testing

For the continuous data, Analyses of Variance (ANOVA) and linear regression were used. For categorical measures, Chi-square tests and binary logistic regression analyses were used. Fisher's exact tests were used when more than 50% of cells had a count less than five. The independent variables (other than ASD) entered into the regression analyses were selected on the basis that they were significantly associated with the dependent variable according to a one-way ANOVA or Chi-square test.

Power calculations

The required sample size was estimated using data from research on similar populations. Analyses were carried out on data from 371 specialist mental health service users with intellectual disability (Underwood et al., 2012). Mean HoNOS-LD score was significantly higher for participants with a clinical diagnosis of ASD (20.8, SD=12.2) than for those without ASD (13.7, SD=9.7, $t(220)=-4.7$, $p<0.01$).

Brereton et al. (2006) found a significant difference of 18.2 on the DBC's Total Problem Behaviour Score between young people with autism or intellectual disability. Knapp et al. (2009) estimated that no adults with intellectual disability and ASD would be in employment,

whilst the Foundation for People with Learning Disability (2007) reported that around 17% of adults with intellectual disability have a job.

Power calculations, carried out by nQuery Advisor software, using a two group t-test or Chi-square test with 0.05 two-sided significance level, found that a sample size of:

- 40 participants in each group would have 80% power to detect a difference in mean HoNOS-LD scores of 7.1
- 29 participants in each group would have 80% power to detect a difference in mean TBPS scores of 18.2
- 50 participants in each group would have 80% power to detect the difference between a proportion of 0.01 and a proportion of 0.17 (odds ratio of 20.277)

Sample size

Preliminary analysis indicated there would be around 400 potential participants eligible for the data study and that around 126 would have a clinical diagnosis of ASD (Underwood et al., 2012). Given the difficulties often experienced when recruiting participants with intellectual disability it was anticipated that it would be possible to recruit around half the number of people approached. Allowing for drop-outs and cases where an individual's clinical diagnosis was not supported by standardised ASD assessment it was decided that all eligible service users with a clinical diagnosis of ASD would be approached in order to achieve a sample size of 50 participants with ASD who would be matched to 50 participants without ASD.

Chapter 9: Results

The study compared the needs, service use, mental health, behaviour and social functioning of those with and without ASD (confirmed by standardised diagnostic assessment). The analyses were designed to determine the extent to which these dependent variables were significantly predicted by presence of ASD and/or other socio-demographic and clinical factors.

Recruitment

During 2009 and 2010, there were 526 service users on the Lambeth, Lewisham and Southwark (LLS) Mental Health in Intellectual Disability (MHID) service caseload. A screen of service users' records identified 149 individuals with a clinical diagnosis of ASD and 344 with no clinical diagnosis of ASD or mention of ASD in their mental health records. Eight service users were ineligible for the study (they were yet to be assessed and there was insufficient information to determine whether they had ASD). In addition, there were 25 service users with ASD traits/behaviour/features who were excluded from the study.

All LLS service users who appeared eligible for the ASD group were approached to take part from January 2009 until December 2010. The response rate was low; 53 (37%) out of 142 eligible participants with a clinical diagnosis of ASD were eventually recruited.

The aim was to match each participant with ASD to a participant without ASD on severity of intellectual disability, gender, age and where possible psychiatric disorder, type of residence and ethnicity. A further exclusion criterion was applied when recruiting participants without ASD. In addition to the criteria described in Chapter 8, a participant was not recruited if they had a diagnosis of or were suspected of having dementia. This was because none of the participants in the ASD group had dementia.

Recruitment of participants without ASD was carried out on a case-by-case basis by identifying the best match or matches for each participant with ASD. If they agreed to take part, these service users were assessed to confirm that they did not have ASD.

As recruitment progressed, an increasing number of participants who had no mention of ASD in their mental health records exceeded the diagnostic threshold on the ADOS and therefore did not meet the study criteria for 'no ASD'. It became clear that there was a lack of service users without ASD who were good matches for the participants with a clinical diagnosis of ASD. Matching on severity of intellectual disability was a particular problem. Only one service user with severe intellectual disability recruited into the study scored below the ADOS threshold for ASD.

When it was not possible to recruit any further matched participants without ASD (because there were no matching service users who had not been approached already) the selection criteria were widened. This was primarily in order to find participants with severe intellectual disability who did not have ASD. The recruitment process was amended as follows:

- The matching criteria were disregarded, in reverse order of the identified priorities, until there were no more eligible service users from Lambeth, Lewisham or Southwark left to approach.
- The sample base was widened to include specialist mental health service users with moderate or severe intellectual disability from Croydon.
- An attempt was made to include participants from other specialist mental health services for adults with intellectual disability. However consultant psychiatrists from these services were unable to identify anyone with severe intellectual disability who did not have ASD or ASD traits.

The number of individuals failing to meet the study criteria for 'no ASD' continued to rise. It became necessary to approach all eligible service users without a clinical diagnosis of ASD who were on the LLS caseload between January 2009 and December 2010 (N=302) and all eligible service users with no clinical diagnosis of ASD and moderate or severe intellectual disability on the Croydon caseload between August and December 2010 (N=30) regardless of whether they were a good match for participants in the ASD group.

In total, 474 specialist mental health service users with intellectual disability were approached to take part in the study. The overall recruitment rate was 27%; 56 (12%) of those approached refused to take part and there was no response from 289 (61%).

Participants

The final number of participants recruited into the study was 129 (see Figure 11.2). There were 53 participants with a clinical diagnosis of ASD and 76 with no clinical diagnosis of ASD. Their characteristics are reported in Appendix VI.

Most participants (59%) were assessed as having capacity to consent to take part in the study. Informants for the data collection interview were paid care staff (60%), family members (31%) and MHID CPNs (4%). One participant refused to consent to an informant being interviewed and answered all items himself. Another participant nominated a friend to be his informant and also took part in the interview.

All informants had known participants for at least three months and had contact with them at least once every two weeks. Informants who were not family members had known participants for an average of 4 years. Eighty-six percent of non-family informants had known the participant for at least 12 months. There was no significant difference between those with and without ASD on informant contact.

ASD assessment

Assessments were carried out for all 129 participants to determine whether they met the study criteria for ASD or 'no ASD'. An Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989) assessment was completed for 113 participants; 88% of the sample. Of the 16 participants that did not take part in an ADOS assessment: four could not be contacted, their consultee refused for four participants, three had sensory impairments, two refused, one was too ill due to a psychiatric disorder, one had physical impairments and one had died.

ADOS assessment

A module 1 (non-verbal) ADOS assessment was used for 27 participants, module 2 (phrase speech) for 12 participants, module 3 (fluent speech) for 19 participants and module 4 (advanced speech) for 55 participants. Table 9.1 shows the proportion of those in each group who exceeded the ADOS thresholds for ASD.

Table 9.1: Results of the ADOS assessments

	Clinical diagnosis of ASD N = 44	**No clinical diagnosis of ASD N = 69**
Exceeding Communication cut-off score for ASD	44	36
Exceeding Social Interaction cut-off score for ASD	44	35
Exceeding cut-off for ASD (total, communication & social interaction scores all exceed cut-offs)	**44**	**24**

The 24 participants with no clinical diagnosis of ASD who exceeded the ADOS threshold were excluded. All of the participants with a clinical diagnosis of ASD exceeded the threshold ADOS for ASD and were included.

Reliability of the ADOS assessments

An inter-rater reliability coding was carried out on 35 ADOS assessments (37%). There was agreement on whether the participant exceeded the ADOS thresholds for ASD on 83% of these assessments and Cohen's kappa was 0.59 ($p<0.001$).

Expert review ASD assessment

An ASD assessment for the 16 participants who did not take part in an ADOS assessment was carried out by a consultant intellectual disability psychiatrist. As detailed in Chapter 9, the participants' informant interview schedule and information from their mental health record were reviewed and used to complete a checklist of ICD-10 criteria for ASD. The results are shown in Table 9.2.

Table 9.2: Results of the ASD assessment for those who did not complete an ADOS

	Clinical diagnosis of ASD N = 9	**No clinical diagnosis of ASD N = 7**
No evidence of ASD or previous assessment had ruled out ASD	**3**	3
Met ICD-10 criteria for ASD	6	**4**

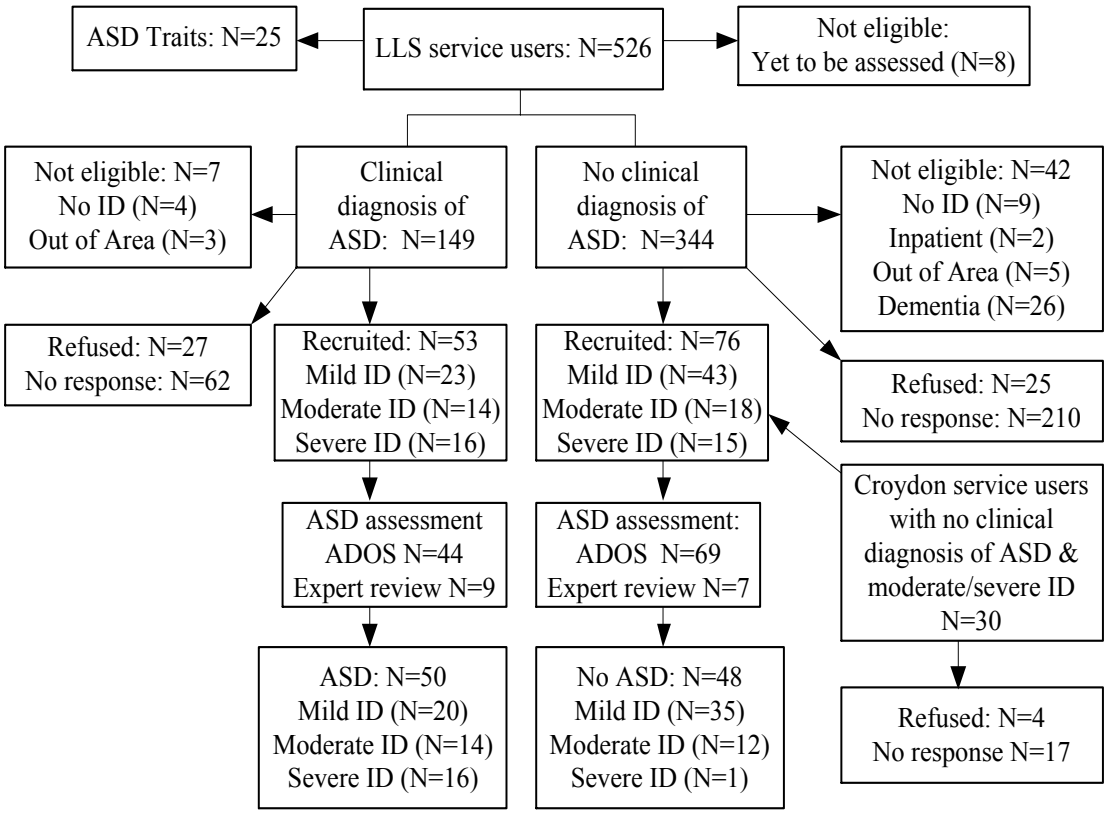
Three participants with a clinical diagnosis of ASD were excluded because they did not appear to meet ICD-10 criteria for ASD according to a review of their mental health record. Four participants with no clinical diagnosis of ASD were excluded because they appeared to meet ICD-10 criteria for ASD.

As Table 9.1 and Table 9.2 showed, 94% of participants with a clinical diagnosis of ASD met the study criteria for ASD. The three participants whose diagnosis was not confirmed did not take part in ADOS assessments. Two people could not be contacted following the informant interview. One participant's records revealed they previously had ADOS and ADI-R assessments at a specialist ASD clinic and did not meet the criteria for a diagnosis. There was evidence from another participant's records that they did not meet ICD-10 criteria for ASD. One participant could not take part due to a visual impairment. A review of their records indicated that while there was evidence that they currently met ICD-10 criteria for ASD they did not appear to have had any social or communication impairments as a child. There was evidence that these had emerged during adulthood.

A high proportion (37%) of the 76 participants with no clinical diagnosis of ASD were excluded because they exceeded the ADOS threshold or met ICD-10 criteria for ASD. The proportions of excluded participants were 19% of those with mild intellectual disability, 33% of those with moderate intellectual disability and 93% of those with severe intellectual disability. Only one person with severe intellectual disability met the study criteria for 'no ASD'.

Without further assessment it was not possible to determine whether the excluded individuals had undiagnosed ASD, ASD traits that would not meet the criteria for ASD or whether there was some other reason that their behaviour during the ADOS assessment meant they exceeded the threshold for ASD. Analyses of data for these excluded participants are reported in Chapter 12. Figure 9.1 shows a detailed flow of participants through the recruitment process.

Figure 9.1: Flow of participants through the study



Following the ASD assessment procedure, 50 participants with ASD and 48 without ASD were included in the study.

Participant characteristics

The remainder of this chapter focuses on the 98 participants who met the study criteria. Unless otherwise indicated in the text or tables, the analyses were based on 50 participants with ASD and 48 participants without ASD.

ASD symptomatology

The two groups were compared to explore differences in ASD symptomatology between them. There were Social Communication Questionnaire (SCQ) data for 93 participants. Table 9.3 shows the results of the SCQ assessments.

Table 9.3: SCQ results for participants with & without ASD

	ASD N = 49	**No ASD N = 44**
Mean SCQ score (SD)	16.2 (4.8)	5.5 (3.1)
Range of SCQ scores	4 to 26	0 to 15
Exceeding cut-off for ASD (≥15)	32 (65%)	1 (2%)

Participants with ASD had a significantly higher mean SCQ score than those without ASD ($F(1,92)=161.04$, $p<0.001$). Participants with ASD were significantly more likely to score 15 or higher on the SCQ ($X^2(1)=40.2$, $p<0.001$). However, some participants with ASD (35%) scored below the SCQ threshold for ASD. All but one of the participants without ASD scored below the ASD threshold[1]. The psychometric properties of the SCQ are shown in Table 9.4.

[1] NB SCQ item responses were used to confirm ASD diagnosis for those without an ADOS assessment but total SCQ score was not.

Table 9.4: Psychometric properties of the SCQ

Cronbach's alpha	0.867
Sensitivity	0.65
Specificity	0.97
Positive Predictive Value	0.97
Negative Predictive Value	0.71

The SCQ had good internal consistency (Cronbach's alpha; George & Mallery, 2010[2]). Compared with the ASD assessment procedure, the SCQ had high specificity and positive predictive value but relatively low sensitivity and negative predictive value. This suggests that any individual scoring above 15 on the SCQ is very likely to have ASD. However, a low score on the SCQ does not necessarily indicate that the person does not have ASD.

Socio-demographic and clinical characteristics

Table 9.5 shows the characteristics of the participants with and without ASD.

Table 9.5: Socio-demographic characteristics of the participants with & without ASD

		ASD	No ASD	Significance test
Age	Mean years (SD) Range	36.4 (12.4) 18 to 68	43.7 (11.6) 20 to 63	F(1,97)=8.92, p=0.004
Severity of ID	Mild Moderate Severe	20 (40%) 14 (28%) 16 (32%)	35 (73%) 12 (25%) 1 (2%)	$\chi^2(2)=17.4$, p<0.001
Gender	Males Females	40 (80%) 10 (20%)	29 (60%) 19 (40%)	$\chi^2(1)=4.51$, p=0.034
Ethnicity	Afro-Caribbean White Other or unclear	19 (38%) 27 (54%) 4 (8%)	15 (31%) 30 (63%) 3 (6%)	$\chi^2(2)=0.731$, p=0.694
Type of residence	With family Residential Independently	21 (42%) 27 (54%) 2 (4%)	11 (23%) 23 (48%) 14 (29%)	$\chi^2(2)=12.4$, p=0.002
Psychiatric disorder	Present Absent	23 (46%) 27 (54%)	41 (85%) 7 (15%)	$\chi^2(1)=16.8$, p<0.001

There were several significant differences between those with and without ASD:

[2] $\alpha \geq 0.9$=excellent, $\alpha \geq 0.8$=good, $\alpha \geq 0.7$=acceptable, $\alpha \geq 0.6$=questionable, $\alpha \geq 0.5$=poor, $\alpha < 0.5$=unacceptable.

- Participants with ASD were younger.
- Participants with ASD were more likely to be male.
- Participants with ASD were more likely to live with family ($\chi^2(1)= 4.1$, $p=0.044$) and less likely to live independently ($\chi^2(1)=11.4$, $p=0.001$).
- Participants with ASD were less likely to have mild intellectual disability ($\chi^2(1)=10.8$, $p=0.001$) and more likely to have severe intellectual disability ($\chi^2(1)=15.3$, $p<0.001$).

Individuals are referred to the mental health in intellectual disability (MHID) service if they have or are suspected of having a psychiatric disorder but also if they have significant impairment of behaviour requiring psychiatric input. On acceptance onto the caseload, all service users are assessed by an intellectual disability psychiatrist for the presence of psychiatric disorder according to ICD-10 criteria (WHO, 1992).

Most participants in the clinical study had a diagnosis of psychiatric disorder.

- Participants with ASD were less likely to have an additional psychiatric disorder than those without ASD.

More than half of the participants with ASD appeared to be receiving specialist mental health services for challenging behaviour rather than a psychiatric disorder.

These results demonstrated that attempts to match the groups with and without ASD were not successful. They also showed that participants with ASD were significantly different from those without ASD on a range of socio-demographic and clinical characteristics including the reason for them receiving specialist mental health services (i.e. whether or not they had been diagnosed with a psychiatric disorder).

Exploratory data analysis

Histograms demonstrating the normal distribution of the standardised residuals for each linear regression analyses are shown in Appendix VI. To meet the assumptions for regression analysis there should be a minimum of 15 participants per independent variable entered into the model (Field, 2000). The study included 98 participants; therefore a maximum of six predictors (five plus presence/absence of ASD) were selected for each analysis.

The independent variables that were entered into each analysis were selected by determining whether there was a significant association between the dependent variable and any of the following: severity of intellectual disability, age, gender, ethnicity, type of residence, presence/absence of psychiatric disorder, needs and service consumption score. There were no occasions on which there were more than six potential predictors and therefore no further analyses were needed in order to choose which independent variables should be entered.

Another assumption of regression analysis is that there is no co-linearity between the independent variables. Analyses showed that there were associations between ASD and: age, gender, type of residence severity of intellectual disability and presence/absence of psychiatric disorder. Although ASD was significantly correlated with these variables the relationships were not strong enough (r was not greater than 0.5; Cohen, 1988) to violate the assumptions of the regression models.

There was a significant correlation, greater than 0.5, between age and type of residence; there was a particularly strong relationship between being younger and living with family. As a result, in cases where both age and type of residence were significantly associated with a dependent variable, only age was entered into the regression analysis. This was because the nature of the relationship is that age would be causal predictor of type of residence rather than vice versa. Further diagnostic analyses found no evidence that there were problems with co-

linearity for any of the regression analyses: tolerance values were greater than 0.6, variance inflation factors were less than two and condition indices were less than 15 (Field, 2000).

It was important to ascertain the relative importance of any factors that were found to be significant predictors of the dependent variables. For linear regression analyses, this was achieved by examining the standardised coefficient (β) of each variable (Field, 2000). For binary logistic regression, this was achieved by examining the exponential of the regression coefficient – Exp (B) – which represents the change in odds resulting from a unit change in the predictor (Field, 2000).

Needs

Participants' needs were measured the Camberwell Assessment of Needs for Adults with Intellectual Disability (CANDID; Xenitidis et al., 2003). In addition, during the administration of the Client Service Receipt Inventory (CSRI), informants were asked an open question about whether the participant had any unmet needs.

CANDID

There were CANDID data for 93 participants. The internal consistency of the CANDID (measured using Cronbach's alpha) was low (α=0.49). Cronbach's alpha increased when the followings items were deleted: Eyesight/hearing, Major mental health problems, Exploitation risk and Sexual expression. Removing all four of these items improved the internal consistency from unacceptable to questionable (α=0.62). Since the revised scale was more reliable than the full 25-item scale it was used in all further analyses. This did not affect the findings of the analyses.

It appeared that although participants had a range of needs (between five and 18 in total), on average the majority were being met (between 33 and 100% of the time). The most commonly

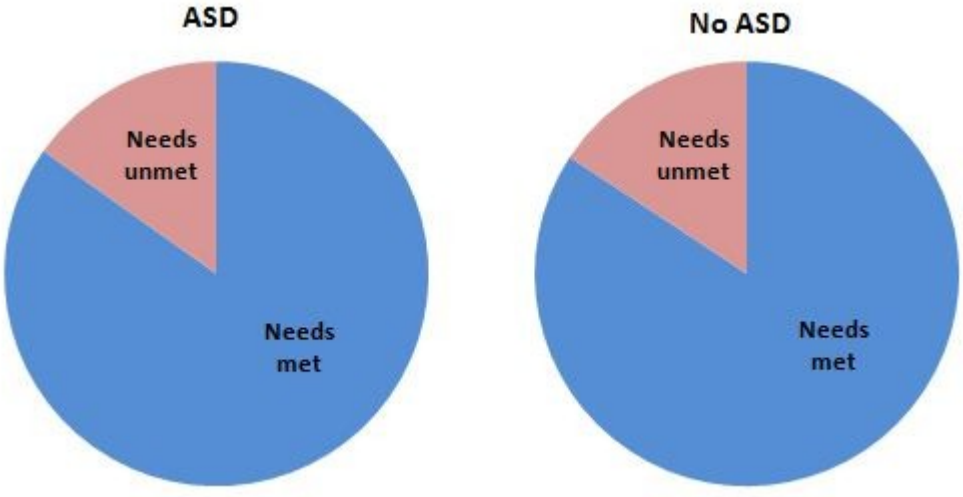
unmet need was Daytime activities. The area with the highest level of need was Welfare benefits with only seven participants not requiring any help in claiming them. The area with the least need was Caring for someone else with only one person (who was in the no ASD group) reporting this was a need (that was unmet). Table 9.6 shows the results for participants with and without ASD using the revised 21-item CANDID scale.

Table 9.6: Revised 21-item CANDID results for participants with & without ASD

	ASD (N =49)	No ASD (N =44)
Mean met needs	**9.5 (2.4)**	**7.5 (2.9)**
Mean unmet needs	1.7 (1.6)	1.4 (2)
Mean total needs	**11.1 (2.4)**	**8.9 (2.9)**
Mean percentage of needs that were unmet	14.9 (15.7)	15.6 (19)

Participants with ASD had significantly more needs and more of those needs were being met than those without ASD ($F(1,92)=15.9$, $p<0.001$; $F(1,92)=12.3$, $p=0.001$). There was no difference between those with and without ASD on participants' number of unmet needs or the proportion of their needs that were going unmet as demonstrated in Figure 9.2.

Figure 9.2: Proportion of participants' needs that were met & unmet



Level of need was divided into high and low (high=total needs≥10). Participants with ASD were significantly more likely to have a high level of total needs compared to those without ASD (78% vs. 46%; $X^2(1)=10.2$, p=0.001).

Higher numbers of total needs and met needs were significantly associated with moderate and severe intellectual disability, not living independently and absence of psychiatric disorder. The only factor associated with unmet needs was type of residence such that:

- Participants in residential placements had a significantly lower number of unmet needs than those in other types of accommodation; they also had a significantly lower proportion of needs that were unmet.

- Those living independently had a significantly higher proportion of their needs that were unmet compared with those in other types of residence.

A linear regression analysis on predictors of total number of needs was carried out. The results are shown in Table 9.7.

Table 9.7: Results of the linear regression on total number of needs

	Unstandardised Coefficients			**Standardised coefficients**		
	B	SE (B)	95% CI (B)	β	t	p
Presence/absence of ASD	.80	.53	-0.25 to 1.9	.15	1.52	.13
Moderate/severe intellectual disability	**2.17**	**.51**	1.2 to 3.2	**.40**	**4.25**	**<.001**
Living independently	**-2.34**	**.67**	-3.7 to -1	**-.32**	**-3.51**	**.001**
Presence of psychiatric disorder	.21	.55	-0.9 to 1.3	.04	.37	.71
Constant	11.22	.61	10 to 21.4		18.40	<.001

The model was statistically significant ($F(1,91)=13.8$, p<0.001) and accounted for 39% of the variance. Severity of intellectual disability and type of residence were significant predictors of total number of needs. Once these were taken into account there was no significant association between needs and presence of ASD. The factor with the highest standardised coefficient was having moderate to severe intellectual disability (β= 0.40).

Thus participants with ASD appeared to have higher levels of need but this was due to the higher rates of moderate and severe intellectual disability in this group.

Informal assessment of need

With regards to the informal identification of needs, 67 participants had at least one unmet need and the average number of unmet needs was 2.2 (slightly higher than that found by the CANDID). The number of unmet needs was very similar for those with and without ASD.

The most commonly mentioned areas of unmet need were employment, college, activities and having more one-to-one support to enable access to the community. Many informants mentioned the need for more activities at weekends, during the evening and over the summer. A range of unmet physical and mental health needs were identified including input for behavioural problems, counselling, psychological therapy, exercise/weight loss and access to dental and chiropody services.

Mental health and social functioning

A snapshot of participants' mental health, behaviour and social functioning was taken using the Health of the Nation Outcome Scale for adult with Learning Disability (HoNOS-LD), Developmental Behaviour Checklist (DBC) and a specially devised social functioning scale for adults with developmental disabilities.

Pattern of psychiatric disorder

As shown earlier in Table 9.5 (page 137) there were 64 participants who were diagnosed with a psychiatric disorder. Table 9.8 shows the pattern of specific diagnoses for these participants.

Table 9.8: Pattern of diagnoses among participants with a psychiatric disorder

Primary diagnosis	ASD (N = 23)	No ASD (N = 41)
ADHD	3 (13%)	1 (2%)
Anxiety disorder	4 (17%)	1 (2%)
Bipolar disorder	5 (22%)	9 (22%)
Depressive disorder	**1 (4%)**	**14 (34%)**
Personality Disorder	0	1 (2%)
Psychotic disorder	10 (44%)	13 (32%)
Other*	0	2 (7%)

* mixed anxiety & depression

There was an overall significant difference between those with and without ASD on the primary diagnosis of psychiatric disorder (Fisher's exact test =14.3, p=0.01). Participants with ASD were less likely to have an additional diagnosis of depression ($X^2(1)=7.3$, p=0.007) than those without ASD.

Of the 64 participants with a psychiatric disorder, 25% had more than one diagnosis (16% of the 98 people with and without ASD). Table 9.9 shows the different diagnoses that these participants had.

Table 9.9: Participants with more than one psychiatric diagnosis

ASD (N=5)		No ASD (N=11)	
Primary diagnosis	**Secondary diagnosis/es**	**Primary Diagnosis**	**Secondary diagnosis/es**
ADHD	Tourette syndrome	Affective disorder	Borderline personality disorder
		Bipolar disorder	Previous harmful use of alcohol
		Depression	Borderline/Antisocial Personality Traits
Anxiety disorder	Hypomania in remission	Depression	Catatonic schizophrenia (in remission)
OCD	Mental & behavioural disorder due to alcohol	Depression	Dissociative convulsions
		Depression	Emotionally unstable personality disorder
		Depression	Past history of psychotic disorder
Schizophrenia	Harmful use of alcohol; Enduring personality change	Emotionally unstable personality disorder	Past history of dysthymia
		PTSD	Psychosis (in remission); Previous harmful use of alcohol
		Psychotic disorder	Impulsive personality traits
		Schizoaffective disorder	Hypomania

Two participants had three diagnoses (one in each group). It appeared that for participants without ASD it was quite common for depressive/mood disorders to be accompanied by an additional problem and for personality disorders to co-occur with other diagnoses. For those with ASD, it was ADHD and anxiety that were accompanied by other disorders. There was evidence of previous or current alcohol problems in both groups.

HoNOS-LD

The HoNOS-LD is a broad measure of health and social functioning focussing on a four week period. There were HoNOS-LD data from the informant interview for 93 participants. For the other five participants, data from a HoNOS-LD assessment carried out by a specialist mental health service clinician during the relevant time period were used. Total HoNOS-LD scores ranged from 2 to 42. One person had a total score higher than 40 (a participant with ASD). There was nothing unusual about this participant and they remained in the analyses. The internal consistency of the HoNOS-LD measured using Cronbach's alpha was acceptable (0.76). Table 9.10 shows the mean score for each group on the HoNOS-LD.

Table 9.10: Mean total scores (& SDs) on the HoNOS-LD for participants with & without ASD

	ASD	**No ASD**	
Total HoNOS-LD	**19.8 (8.2)**	**11 (6.1)**	F(1,97)=36.5, p<0.001
HoNOS-LD Neuro-cognitive functioning	**4.3 (3.3)**	**1.8 (1.8)**	F(1,97)=21.9, p<0.001
HoNOS-LD Mental/behaviour subscale	**9.1 (4.4)**	**4.5 (3.5)**	F(1,97)=33.5, p<0.001
HoNOS-LD Health/social functioning	**6.3 (4.1)**	**4.7 (3.6)**	F(1,97)=4.4, p=0.039

Participants with ASD had a significantly higher mean total HoNOS-LD score compared to those without ASD indicating lower health and social functioning. The mean difference in HoNOS-LD scores between those with and without ASD was 8.8 'points'. Participants with

ASD had significantly higher scores on all three HoNOS-LD subscales than those without ASD.

Cronbach's alpha for the subscale scores ranged from poor for Health/social functioning (0.596), to questionable for Mental/behavioural problems (0.65) and acceptable for Neuro-cognitive functioning (0.73).

Total HoNOS-LD score was significantly and positively correlated with number of unmet needs, number of met needs and total number of needs ($r=0.51$, $p<0.001$; $r=0.25$, $p=0.015$; $r=0.56$, $p<0.001$). It was also significantly, positively correlated with proportion of needs that were unmet ($r=0.37$, $p<0.001$). It appears that the more needs a person has the poorer their health and social functioning.

Linear regression analyses found that ASD and severity of intellectual disability were independent significant predictors of HoNOS-LD score. Total number of needs, unmet needs and proportion of need that were unmet were also significant predictors when each was entered into the analysis.

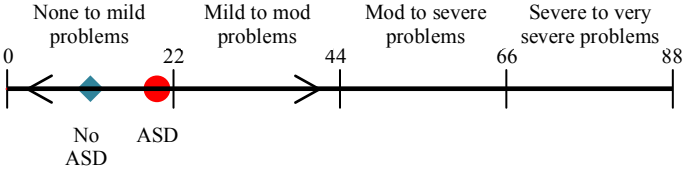
The model that included number of unmet needs accounted for the greatest variance (56%) and is shown in Table 9.11. The model was statistically significant ($F(5,90)=21.7$, $p<0.001$). The variable with the highest standardised coefficient was the presence of ASD.

Table 9.11: Results of the linear regression for total HoNOS-LD score

	Unstandardised Coefficients			**Standardised coefficients**		
	B	SE (B)	95% CI (B)	β	t	p
Presence/absence of ASD	**7.14**	**1.43**	**4.3 to 10**	**.45**	**5**	**<.001**
Severity of intellectual disability	**2.55**	**.93**	**0.7 to 4.4**	**.25**	**2.75**	**.007**
Presence of psychiatric disorder	1.14	1.51	-1.9 to 4.1	.07	0.75	.455
Age	0.01	.05	- 0.1 to 0.1	.02	0.28	.783
Number of unmet needs	**1.95**	**.33**	**1.3 to 2.6**	**.44**	**5.86**	**<.001**
Constant	5.56	2.76			2.01	0.05

The maximum total score of the HoNOS-LD is 88 but participants' scores ranged from two to 42. This indicates that most had good health and social functioning. The mean scores of participants with and without ASD fell within the range of none to mild problems (total score: 1-22; see Figure 9.3). However some participants' scores (N=21; 20%) fell into the range of mild to moderate problems (total score: 23-44).

Figure 9.3: Participants' range of scores on the HoNOS-LD



Participants with ASD were significantly more likely to fall within the range of mild to moderate problems (total score>22) than those without ASD (38% vs. 4%; $X^2(1)=16.7$, $p<0.001$). As were those with severe intellectual disability compared to those with mild/moderate intellectual disability (47% vs. 16%; $X^2(1)=7.8$, $p=0.005$).

Binary logistic regression revealed that presence of ASD and number of unmet needs were significant predictors of having mild to moderate problems (HoNOS-LD score>22). The results are shown in Table 9.12. Presence of ASD and proportion of needs that were unmet were also significant predictors of having mild to moderate problems when this measure of need replaced number of unmet needs in the analysis.

Table 9.12: Results of the logistic regression for total HoNOS-LD greater than 22

	B	SE (B)	p	Exp (B)	95% CI for Exp (B)
Presence/absence of ASD	**3.1**	**1**	**0.002**	**21.9**	3 to 160.1
Severe intellectual disability	0.29	0.7	0.664	1.3	0.4 to 5
Number of unmet needs	**0.56**	**0.2**	**0.001**	**1.7**	1.2 to 2.4
Constant	-4.6	1.1	<0.001		

The factor with the highest odds ratio was presence/absence of ASD (OR= 21.9), the confidence intervals of which did not overlap with any of the other variables.

Developmental Behaviour Checklist for Adults (DBC)

The DBC measures psychopathology over six months. The DBC was completed for 93 participants: 49 with ASD and 44 without ASD. Total Problem Behaviour Scores (TPBS) ranged from 8 to 99. One participant with ASD appeared to be an outlier with a score of 99. Since the next lowest TPBS was much lower (85) this person was removed from the DBC analyses. TBPS scores were normally distributed.

The internal consistency of the TBPS measured using Cronbach's alpha was good (0.899). HoNOS-LD total scores were significantly correlated with the DBC TPBS ($r=0.69$, $p<0.001$). Table 9.13 shows the DBC results for participants with and without ASD.

Table 9.13: Developmental Behaviour Checklist results for participants with & without ASD

	ASD (N = 48)	**No ASD (N = 44)**
Mean (SD) TPBS	**54.2 (14.4)**	**29.2 (14.3)**
Psychiatric case (TBPS≥31)	**45 (94%)**	**17 (39%)**
Psychiatric case (TBPS≥51)	**29 (60%)**	**5 (11%)**

Participants with ASD had a significantly higher TPBS compared to those without ASD ($F(1,91)=69.9$, $p<0.001$); indicating poorer mental health.

Participants with ASD were significantly more likely to exceed the cut-off scores for psychiatric caseness than those without ASD (TBPS≥31: $X^2(1)=31.7$, $p<0.001$; TBPS≥51: $X^2(1)=23.7$, $p<0.001$). The mean difference between the groups on TPBS was 25 points. This is greater than the level of clinical significance adapted from the DBC-P (TBPS of 19; see Chapter 10).

Exploratory analyses found that TPBS was significantly associated with severity of intellectual disability, age, type of residence, presence of psychiatric disorder and total

number of needs (see Appendix VI). Therefore, five variables were entered in to a linear regression as predictors of TPBS (see Table 9.14)[3]. The model accounted for 51% of the variance and was statistically significant ($F(5,91)=18.1$, $p<0.001$).

Table 9.14: Results of the linear regression for Total Problem Behaviour Score

	Unstandardised Coefficients			**Standardised coefficients**		
	B	SE (B)	95% CI (B)	β	t	p
Presence/absence of ASD	**21.02**	**3.6**	**13.9 to 28.1**	**0.56**	**5.9**	**<0.001**
Severity of intellectual disability	-1.02	2.5	-5.9 to 3.9	-0.04	-0.4	0.68
Presence of psychiatric disorder	2.99	3.6	-4.1 to 10.1	0.08	0.8	0.403
Age	-0.2	0.13	-0.5 to 0.05	-0.13	-1.6	0.114
Total number of needs	**1.99**	**0.6**	**0.8 to 3.2**	**0.3**	**3.3**	**0.001**
Constant	18.16	7.8			2.3	0.023

The only significant predictors of TPBS were presence of ASD and total number of needs. Presence of ASD had the highest standardised coefficient (β=0.56).

As with the HoNOS-LD results, participants' DBC scores were fairly low (range eight to 85) considering the scale has a maximum score of 218 (see Figure 9.4).

Figure 9.4: Participants' range of scores on the DBC

As this figure shows the mean TBPS of the group with ASD was above the 51-point cut-off score for psychiatric caseness. Whereas, the mean score for the group without ASD was below the lower (more sensitive) 31-point cut-off. None of the participants in the study scored above the high specificity cut-off of 96.

[3] Type of residence not entered due to the high correlation with age (see Exploratory data analysis)

In addition to the presence of ASD, exceeding the cut-off score of 51 was significantly associated with having severe intellectual disability ($X^2(1)=4.3$, $p=0.039$) and type of residence ($X^2(2)=14.4$, $p=0.001$). None of the participants who lived independently exceeded the cut-off. However, 37% of those in residential placements and 57% of those living with family scored higher than 50.

Binary logistic regression analysis revealed that presence of ASD, living with family and total number of needs were significant predictors of having a TBPS greater or equal to 51. The results are shown in Table 9.15. The odds ratio for ASD was 10.9. This was higher than the odds ratios for the other variables but confidence intervals overlapped with living with family.

Table 9.15: Logistic regression results for psychiatric caseness on the DBC

	B	SE (B)	p	Exp (B)	95% CI Exp (B)
Presence/absence of ASD	**2.4**	**0.72**	**0.001**	**10.9**	2.7 to 44.3
Moderate/severe intellectual disability	-1.2	0.72	0.098	0.3	0.1 to 1.3
Living with family	**1.3**	**0.6**	**0.035**	**3.6**	**1.1 to 11.5**
Total number of needs	**0.5**	**0.2**	**0.001**	**1.7**	**1.2 to 2.3**
Constant	-7.5	1.8	<0.001	0.001	

There was significant agreement (according to Cohen's kappa) between the DBC and HoNOS-LD on whether an individual had mild to moderate problems/exceeded the threshold for psychiatric caseness ($\kappa=0.44$, $p<0.001$).

DBC subscales

Participants scores on the DBC subscales described by Mohr et al (2004) are shown in Table 9.16. Participants with ASD had significantly higher scores on the Self-absorbed, Communication disturbance and Social relating DBC subscales. Although they also had higher means scores on the Disruptive, Anxiety/anti-social and Depressive subscales these differences were not statistically significant.

Table 9.16: Mean (SD) DBC subscale scores for participants with & without ASD

	ASD N = 48	**No ASD N = 44**	
Disruptive	11 (5.2)	9.5 (5.2)	F(1,91)=2.03, p=0.158
Self-absorbed	**12.9 (6)**	**3.9 (3.4)**	**F(1,91)=77.4, p<0.001**
Communication disturbance	**5.7 (3.3)**	**4 (3)**	**F(1,91)=6.2, p=0.014**
Anxiety/anti-social	2.7 (1.4)	2.1 (1.7)	F(1,91)=3.3, p=0.073
Social relating	**5.8 (2.5)**	**1.7 (1.8)**	**F(1,91)=81.3, p>0.001**
Depressive	3.2 (3.3)	2.6 (2.3)	F(1,91)=1.1, p=0.305

A subscale of 34 items relating to mental health rather than behavioural problems was derived from the DBC (see Appendix VI). The scale had acceptable internal consistency (Cronbach's alpha=0.74). Mean score on the DBC mental health subscale was significantly higher for participants with ASD (13.6, SD=6.5) than for participants without ASD (9.8, SD=5.5, F(1,91)=8.8, p=0.004).

A higher DBC mental health subscale score was also significantly associated with having a diagnosis of psychiatric disorder, living with family, younger age and higher total number of needs. There was not a significant association between DBC mental health score and severity of intellectual disability.

Five variables were entered in to a linear regression as predictors of DBC mental health subscale score (see Table 9.14)[4]. The model accounted for 34% of the variance and was statistically significant (F(5,91)=8.9, p<0.001).

Table 9.17: Results of the linear regression for the mental health subscale of the DBC

	Unstandardised Coefficients			**Standardised coefficients**		
	B	SE (B)	95% CI (B)	β	t	p
Presence/absence of ASD	**4.1**	**1.4**	**1.3 to 6.8**	**0.33**	**2.97**	**0.004**
Severity of intellectual disability	-1.42	1	-3.3 to 0.5	-0.17	-1.5	0.14
Presence of psychiatric disorder	**4.83**	**1.4**	**2.1 to 7.5**	**0.37**	**3.5**	**0.001**
Age	**-0.12**	**0.05**	**-0.2 to -0.02**	**-0.23**	**-2.4**	**0.018**
Total number of needs	**0.73**	**0.2**	**0.3 to 1.2**	**0.33**	**3.2**	**0.002**
Constant	4.7	3	-1.2 to 10.7		1.6	0.119

[4] Type of residence not entered due to the high correlation with age (see Exploratory data analysis)

Presence of ASD, presence of psychiatric disorder, age and total number of needs were all significant predictors of mental health subscale score. Presence of psychiatric disorder had the highest standardised coefficients such that participants without a diagnosis had a higher mental health subscale score (β=0.37).

The issues that participants had the most problems with on the DBC (items that had a mean score ≥ 1) were: poor attention span, impatience, impulsivity, poor sense of danger and being easily distracted. Three of these items were included in a hyperactivity subscale of the children's DBC (becomes overexcited, poor attention span, impatient, impulsive, noisy/boisterous and overactive; Einfeld & Tonge, 2002).

Participants with ASD had a significantly higher total score for these six items compared to those without ASD (6.1 vs. 4; $F(1,91)=17.2$, $p<0.001$). However, there were no significant differences between those with and without ADHD[5] on the total score of these items (6.7 vs. 5; $F(1,91)=1.1$, $p=0.297$) or the five items that participants scored highly on (7 vs. 5.4; $F(1,91)=0.9$, $p=0.337$).

Problem behaviour

Problem behaviour was measured in two ways: by totalling the six behavioural items on the HoNOS-LD and totalling 72 items on the DBC that relate to problem behaviours (see Appendix VI). The results are shown in Table 9.18 below.

Table 9.18: Problem behaviour scores of participants with and without ASD

	ASD	**No ASD**	
HoNOS-LD Behaviour subscale	**6.3 (3.6)**	**2.7 (2.7)**	$F(1,97)=30.8$, $p<0.001$
DBC Behaviour subscale	**39.2 (10.6)**	**18.8 (10.3)**	$F(1,91)=87$, $p<0.001$

[5] The number of participants with ADHD and a DBC score was 3 (2 with ASD and 1 without ASD).

The HoNOS-LD problem behaviour subscale had questionable internal consistency (Cronbach's alpha=0.65). Participants with ASD had significantly higher levels of problem behaviour according to the HoNOS-LD. A higher HoNOS-LD problem behaviour score was also significantly associated with more severe intellectual disability, absence of a psychiatric disorder and total number of needs.

The DCB behaviour subscale had good internal consistency (Cronbach's α=0.89). Participants with ASD had significantly higher levels of problem behaviour according to the DBC. A higher DBC problem behaviour score was also significantly associated with more severe intellectual disability, absence of a psychiatric disorder, not living independently, younger age and total number of needs.

Many of the items included in the DBC behaviour subscale were related to ASD symptoms. The DBC for adults does not have an ASD subscale. However, it contains very similar items to the DBC-P (the children's version of the DBC) which has an item ASD subscale (Einfeld & Tonge, 2002; see Appendix VI). These items were removed from the total DBC behaviour score to explore whether the difference between participants with and without ASD remained. This subscale had acceptable internal consistency (Cronbach's α=0.78).

Participants with ASD had a significantly higher mean DBC problem behaviour score when ASD items were removed than those without ASD (18.8, SD=6.8 vs. 11.4, SD=7; $F(1,91)=26.2$, $p<0.001$). Once these items had been removed there was no longer an association between the problem behaviour score and age or presence/absence of a psychiatric disorder.

Linear regression found that DBC problem behaviour score (minus ASD items) was significantly predicted by ASD and total number of needs (see Table 9.19). The model accounted for 29% of the variance and was statistically significant ($F(4,91)=8.8$, $p<0.001$).

Table 9.19: Linear regression for DBC problem behaviour subscale minus ASD items

	Unstandardised Coefficients			**Standardised coefficients**		
	B	SE (B)	95% CI (B)	B	t	p
Presence/absence of ASD	**5.6**	**1.6**	**2.5 to 8.8**	**0.36**	**3.6**	**0.001**
Mild intellectual disability	0.08	1.7	-3.2 to 3.4	0.005	0.05	0.962
Living independently	-0.86	2.1	-5.1 to 3.4	-0.041	-0.4	0.688
Total number of needs	**0.71**	**0.3**	**0.09 to 1.3**	**0.26**	**2.3**	**0.025**
Constant	**5.3**	**3.8**	-2.3 to 12.9		1.38	0.17

Presence of ASD had the highest standardised coefficent ($\beta=0.36$).

Social functioning

This section explores associations between presence of ASD and measures of social functioning including communication, independence, employment, activities and relationships. These factors are then brought together using the composite social functioning scale for adults with developmental disabilities.

Communication

Participants with ASD were more likely to be non-verbal[6] (28%) than those without ASD (2%; $X^2(1)=12.7$, $p<0.001$). Among the 15 participants who were not able to express themselves verbally, 8 were able to use other means to express their basic needs to familiar people. The remaining seven participants (all of whom had ASD) were unable to express their needs[7].

[6] Not able to talk in short phrases as sourced from SCQ or if unavailable by case note review.
[7] Information sourced from expressive communication item on HoNOS-LD

The majority of participants (93%) were able to understand words or signed communications about their needs[8]. The remaining participants were only able to understand single words and some signs for basic needs or had little understanding of others' attempts at communication. Only one of these participants did not have ASD; however this was confirmed by expert review not by ADOS assessment.

Independence

As described in Table 9.5, few participants lived independently and those with ASD were significantly less likely to do so. This group was also significantly younger than those without ASD, but the majority (over 75%) were over 25 years of age. Individuals living in residential placements or with family often have a high degree of independence with the ability to come and go as they please; others receive 24-hour supervision. The majority of participants (56%) were supervised by at least one other person whenever they were out in the community. Participants with ASD were significantly less likely to be able to leave their residence alone than those without ASD (26% vs. 63%, $X^2(1)=13.2$, $p<0.001$).

Employment

Table 9.20 shows employment rates among the participants. Only 26 (27%) had ever worked and even fewer (16%) were employed at the time of the informant interview. The number of hours that participants worked varied greatly from just two per week up to eight hours a day, five days a week. Only one participant worked full-time (more than 25 hours a week).

Participants with ASD were less likely to have ever been employed than those without ASD ($X^2(1)=8.6$, $p=0.003$). Participants with ASD were less likely to be currently employed than those without ASD ($X^2(1)=7.97$, $p=0.005$). It appeared that among those with a job,

[8] Information sourced from receptive communication item on HoNOS-LD

participants with ASD worked more hours per week than those without ASD but this difference was not statistically significant.

Table 9.20: Employment status of participants with & without ASD

	ASD	No ASD
Ever worked*	**7 (14%)**	**19 (40%)**
Currently employed	**3 (6%)**	**13 (27%)**
Full-time employed	0	1
Part-time employed	1	8
Supported/sheltered employment	1	1
Voluntary work	1	3
Mean (SD) hours spent working per week (Range)	17 (13.5) 3 to 30	13.3 (11.3) 2 to 40

*information not available for one participant in the no ASD group

Scheduled activities

Table 9.21 shows the number of hours of activities that participants were taking part in each week at the time of their informant interview. These were made up of time spent at work, college, day centres, social clubs, one-to-one activities with a support worker or other activities (e.g. a music session or going to the gym). The number of participants who had no scheduled activities is also shown. The overall level of activity among participants was fairly low (16-17 hours per week on average).

Table 9.21: Weekly scheduled activities of participants with & without ASD

	ASD	No ASD
Mean (SD) hours per week	15.1 (13.3)	13.2 (9.8)
No scheduled activities	10 (20%)	5 (10%)
Mean (SD) hours per week for those with scheduled activities	N=40 18.9 (12.3)	N=43 14.7 (9.2)

There was not a significant difference between those with and without ASD on the mean number of hours of activities they took part in each week. There appeared to be more participants with ASD who did not take part in any activities. This difference was not significantly significant. When only participants who took part in activities were included

those with ASD appeared to have more hours of activity per week than those without ASD however this difference was not statistically significant.

Relationships

Most (93%) of the participants were not in a relationship at the time of the informant interview. One person with ASD was in a relationship. Among those without ASD, five were in a relationship and one was divorced. One participant without ASD had adult children who lived with her and two participants without ASD had children who had been taken into care. Many participants did not lead active social lives (see Table 9.22). Most had no particular friends and few met up with friends regularly.

Table 9.22: Social life of participants with and without ASD

	ASD (N = 49)	No ASD (N = 44)
Has friends	**13 (27%)**	**24 (55%)**
Meets friends regularly	**4 (9%)**	**15 (37%)**

Participants with ASD were less likely to have any friends than those without ASD ($X^2(1)=7.6$, p=0.006). They were also less likely to meet up with friends regularly compared to those without ASD ($X^2(1)=10.2$, p=0.001).

Social functioning scale

Ratings for communication, community life, independence, social life and structured activity were combined to produce an overall composite score (as described in Chapter 8). Participants' social functioning was then categorised as shown in Table 9.23 and a total score calculated. A higher score indicated better social functioning.

The internal consistency of the scale measured using Cronbach's alpha was 0.64.

Table 9.23: Results for the social functioning scale for participants with & without ASD

Rating	ASD (N = 50)	No ASD (N = 44)	
Mean score (SD)	**8.1 (2.9)**	**10.3 (2.3)**	**F(1,93)=16.4, p<0.001**
Excellent	3 (6%)	8 (18%)	**Fisher's exact test= 13.2, p=0.006**
Good	15 (30%)	24 (55%)	
Fair	24 (48%)	10 (23%)	
Poor	6 (12%)	2 (5%)	
Very poor	2 (4%)	0	

Most participants had a fair to good rating of social functioning. Few of those with ASD had an excellent rating and eight had a poor or very poor rating. By contrast few of those without ASD had a poor level of social functioning and eight had an excellent rating. There were significant differences between participants with and without ASD on their total score and which rating of social functioning they had.

Social functioning was also significantly associated with severity of intellectual disability (decrease of around two points as severity increased), presence of psychiatric disorder (those with no diagnosis had poorer social functioning) and total number of needs (those with higher needs had poorer social functioning). These factors and ASD were entered into a linear regression with social functioning score as the dependent variable.

Type of residence was not entered into the regression analyses as living independently was part of the formulation for social functioning score. There was not a significant difference in social functioning score between those living in residential placements and those living with their family.

The regression model was statistically significant ($F(4,91)=20.8$, $p<0.001$) and accounted for 49% of the variance in social functioning scores. The results are shown in Table 9.24. Presence of ASD was not a significant predictor of social functioning once severe intellectual disability, presence of a psychiatric disorder and total number of needs had been taken into account.

Table 9.24: Results of the linear regression for social functioning score

	Unstandardised Coefficients			Standardised coefficients		
	B	SE (B)	95% CI (B)	β	t	p
Presence/absence of ASD	-.1	.49	-1.1 to 0.9	-.02	-.19	.848
Severe intellectual disability	**-2.20**	**.66**	-3.5 to -0.9	**-.31**	**-3.35**	**.001**
Presence of psychiatric disorder	**1.41**	**.52**	0.4 to 2.4	**.25**	**2.72**	**.008**
Total number of needs	**-.34**	**.08**	**-0.5 to -0.2**	**-.35**	**-4.11**	**<.001**
Constant	12.14	.94			12.97	<.001

Further analyses found that total DBC and DBC behaviour scores were significantly correlated with social functioning (r=-.33,p=0.01 and r=-0.38, p<0.01). However, DBC mental health score was not significantly correlated with social functioning and neither was the DBC behaviour subscale once ASD items had been removed. Total DBC and DBC behaviour score were not significant predictors of social functioning when entered into the linear regression.

Service use and intervention

Data on participants' receipt of services and intervention were collected during the case note review and during the informant interview using the Client Service Receipt Inventory (CSRI). For both methods the period covered was the 12 months preceding the informant interview.

Health service use

Table 9.25 shows participants' health service use. The table shows the number of participants with at least one visit and the mean number of visits they had (i.e. those who did not have any visits were excluded from the mean calculations).

There was no difference between participants with and without ASD on whether they had visited their general practitioner (GP). However, among those who visited their GP at least once, those with ASD had fewer appointments than those without ASD (F(1,75)=4.1,

p=0.048). There were some very high users of GP services among those without ASD: three had visited their GP on average more than once every two weeks. When these participants were removed the difference between those with and without ASD for GP visits was no longer statistically significant.

Table 9.25: Health service use of participants with & without ASD

		ASD (N=50)	No ASD (N= 44)
General Practitioner	N (%) with ≥ 1 visit Mean no. of visits	39 (78%) **4.3 (3.5)**	37 (77%) **7.3 (8.8)**
Other primary care[$]	N (%) with ≥ 1 visit Mean no. of visits	38 (76%) 5.4 (7.7)	37 (77%) 7.1 (9.5)
Secondary care*	N (%) with ≥ 1 visit Mean no. of visits	20 (40%) 11.9 (17.4)	25 (52%) 10.2 (15.9)
Accident & Emergency	N (%) with ≥ 1 visit Mean no. of visits	**2 (4%)** 1 (0)	**11 (23%)** 2.2 (2.4)
Inpatient days[#]	N (%) with ≥ 1 visit Mean no. of days	**0**	**5 (10%)** 6.8 (8.3)

Bold results indicate a statistically significant difference between those with and without ASD. [$]Includes primary care nurse, dentist, optician, chiropodist. *Includes alternative therapist, audiology, blood clinic, cardiology, colo-rectal clinic, dental hospital, dermatology, diabetes clinic, endoscopy, neurology, oncology, ophthalmology, rheumatism clinic, scans, X-ray & hospital department unclear.
[#]Excludes days spent as a psychiatric inpatient.

There was no difference between the groups on whether participants had visited other primary care clinicians or secondary care services in the last 12 months. There was no significant difference between those with and without ASD on the mean number of visits to any of these services.

Participants with ASD were significantly less likely to have visited Accident and Emergency (A&E) (X^2=(1)=7.6, p=0.006) or been admitted as an inpatient to hospital for medical reasons than those without ASD (X^2(1)=5.5, p=0.025[9]).

[9] P value for Fisher's exact test

Physical health problems

Participants' physical health was explored to establish whether differences in the needs of those with and without ASD could account for the above differences in service use. Table 9.26 details the rates of epilepsy, visual/hearing impairments and physical disabilities/health problems among those in each group (as recorded in participants' mental health record).

Table 9.26: Physical disability & health problems of participants with & without ASD

	ASD	No ASD
Epilepsy	8 (16%)	6 (13%)
Sensory impairment	6 (12%)	2 (4%)
Other physical health problem or disability[#]	**15 (30%)**	**26 (54%)**
Total number with any disability/health problem*	26 (52%)	30 (63%)

[#]See Appendix VI for a list of the problems included. *Several participants had more than one disability or health problem

Participants with ASD were significantly less likely to have a physical disability/health problem (other than epilepsy or sensory impairment) than those without ASD ($X^2(1)=5.88$, $p=0.015$).

Items from the CANDID and HoNOS-LD relating to physical health were explored. Although a lower proportion of participants with ASD had physical health needs on the CANDID than those without ASD this difference was not significant (35% vs. 55%; $X^2(1)=3.7$, $p=0.054$). Among those with a physical health need, around 80% of those with and without ASD were having those needs met. However, according to the HoNOS-LD, participants with ASD were significantly less likely to have 'increased incapacity due to physical problems' (38% vs. 60%; $X^2(1)=4.9$, $p=0.026$).

It appeared that participants with ASD had fewer physical health needs than those without ASD. This could explain why they used fewer emergency and inpatient health services.

Social service use

Participants' consumption of residential services was explored along with their support staff and day centre use.

Residential service use

As described in Table 9.5 on page 137, around half the participants lived in residential placements. More participants with ASD lived in a residential placement (54%) than those without ASD (44%) but this difference was not statistically significant. Some participants lived alone in these placements but most shared facilities with other service users. The majority of these placements had at least one member of staff on duty throughout the day and night (see Table 9.27).

Participants with ASD lived in residential placements with significantly fewer service users than those without ASD ($F(1,46)=4.09$, $p=0.049$). Participants with ASD lived in placements with significantly more staff per service user: during the day, over night and over 24hours.

Table 9.27: Staff provision in residential placements of participants with & without ASD

Mean (SD)	**ASD (N=27)**	**No ASD (N= 20*)**
Number of residents (incl. participant) Range	**3.9 (1.6)** 2 to 9	**5.2 (2.7)** 1 to 11
Number of day staff/ No. per service user[#]	**3.4 (0.1)** **1 (0.4)**	**2.6 (1.2)** **0.6 (0.2)**
Number of overnight staff No. per service user[#]	1.6 (1.1) **0.5 (0.3)**	1.2 (0.8) **0.3 (0.3)**
Total number of staff/ No. per service user over 24 hours[#]	**5 (1.9)** **1.4 (0.6)**	**3.8 (1.8)** **0.8 (0.5)**

*information unavailable for 1 participant without ASD
[#] information unavailable for 1 participant with ASD

Participants with ASD in residential placements appeared to need a higher level of staff input/supervision than those without ASD. It is important to note that participants lived in residential placements that served a mixture of individuals with or without ASD. Therefore,

although those with ASD appeared to live in households where residents needed a higher level of support this cannot be directly attributed to the participant or whether they had ASD.

Support staff and day centre use

Table 9.28 details participants' use of support staff. This does not include staff from residential placements unless the participant was specifically allocated a set number of one-to-one support hours. Participants' use of day centres is also reported.

Table 9.28: Support staff & day centre use of participants with & without ASD

	ASD	**No ASD**
Receiving support	14 (28%)	18 (38%)
Mean (SD) hours of support/week	13.7 (10.8)	8.7 (6)
Attending a day centre	16 (32%)	15 (31%)
Mean (SD) hours per week at day centre	**18.9 (9.2)**	**10.6 (8)**

A smaller proportion of participants with ASD were receiving support compared to those without ASD however this difference was not statistically significant. Although participants with ASD who received support had more hours per week on average than those without ASD this difference was not statistically significant.

Almost a third of participants regularly attended a day centre for adults with intellectual disability. Those with ASD who attended a day centre did so for significantly more hours per week than those without ASD ($F(1,30)=7.2$, $p=0.012$). The difference in means between the groups was over 8 hours (the equivalent of about one day per week).

Mental health service use

Table 9.29 shows the specialist mental health service use of the participants. When a check was carried out in August 2011 a number of participants had been discharged but the majority

of participants (79%) were still receiving specialist mental health services for adults with intellectual disability.

Table 9.29: Specialist mental health service characteristics of participants

	ASD	No ASD
Current specialist mental health service user[#]	37 (74%)	40 (83%)
Service user at time of informant interview	47 (94%)	42 (88%)
Mean (SD) number of months between discharge & interview	6 (6) 1.5 to 13	9.5 (11) 1 to 26
Mean (SD) number of months since referral to specialist mental health services[$]	79 (64) 4 to 284	74 (59) 4 to 271

[#]on August 15th 2011. [$]measured at date of informant interview.

Nine participants had been discharged before their informant interview took place (no significant difference in number who had been discharged in each group). There was no significant difference between the groups with and without ASD on the length of time between participants' discharge and their informant interview.

The average length of time that had elapsed between participants' referral to specialist mental health services and their informant interview was similar in each group (around 6 to 6½ years). The majority (89%) of participants were referred at least 12 months prior to their informant interview. The most recent service user was referred in August 2010 (their informant interview took place four months later). The participant who had been a specialist mental health service user the longest was referred in 1986; a female with ASD she was discharged to her GP's care in December 2009 (two months after the informant interview).

Specialist mental health service consumption

Table 9.30 shows the specialist mental health service use of participants with and without ASD in the 12 months prior to their informant interview. Nine participants had no contact with specialist mental health services for people with intellectual disability during this time;

six had been discharged from the service and three were current service users. Removing these participants had no effect on the results so they remained in the service use analyses.

Table 9.30: Appointments with specialist mental health team members over 12 months

	ASD	**No ASD**
On CPA	**6 (12%)**	**15 (31%)**
No specialist mental health service use	6 participants (2 current users)	3 participants (1 current user)
	Mean number of appointments (SD) Range	
Psychiatrist	2.7 (1.8) 0 to 8	2.7 (2) 0 to 9
CPN	**1.3 (4.3) 0 to 21**	**5.8 (9) 0 to 31**
Total specialist mental health service appointments	**4 (5.3) 0 to 26**	**8.5 (9.7) 0 to 40**

Participants with ASD were significantly less likely to be on the Care Programme Approach (CPA) than those without ASD ($X^2(1)=5.39$, $p=0.02$).

Participants with the highest levels of service use were those on CPA. In accordance with this participants with ASD had significantly fewer appointments ($F(1,97)=9.9$, $p=0.002$) with a CPN than those without ASD. As a result they also had fewer total number of appointments ($F(1,97)=8$, $p=0.006$). When those on CPA were removed from the analyses there were no significant differences between those with and without ASD.

Other mental health service consumption

Many participants received other mental health services. Table 9.31 shows participants' appointments with mental health staff outside of the specialist mental health service for adults with intellectual disability.

Table 9.31: Appointments with other mental health team members over 12 months

		ASD	No ASD
ID Psychologist	N (%) with ≥ 1 visit Mean no. of visits	9 (18%) 6.8 (6.5)	16 (33%) 7.7 (7.1)
ID Behaviour Support Worker	N (%) with ≥ 1 visit Mean no. of visits	**15 (30%)** 4.9 (5.6)	**5 (10%)** 6.6 (9.4)
Other mental health appointment[$]	N (%) with ≥ 1 visit Mean no. of visits	**2 (4%)** 10.5 (13.4)	**9 (19%)** 17 (28.8)
Psychiatric inpatient stays	N (%) with ≥ 1 stay Mean no. of days	1 (2%) 14	3 (6%) 16 (10.1)

[$]Includes mainstream community mental health team psychiatrists, psychologists & social workers, Home Treatment Team and mental health Liaison Nurses/Psychiatrists

Participants with ASD were significantly more likely to have seen an intellectual disability behaviour support worker than those without ASD ($X^2(1)=5.78$, $p=0.016$). The proportions were reversed for those who saw a psychologist but the difference was not significant. Participants with ASD were significantly less likely to have had contact with another mental health service ($X^2(1)=5.3$, $p=0.021$). Only four participants were admitted to a psychiatric inpatient service; there were no differences in inpatient service use between those with and without ASD.

Less than half (41%) of the 34 participants with no diagnosis of psychiatric disorder were accessing behaviour support services. Only 21% were accessing psychology services and 44% were not accessing either of these services.

Service consumption scores

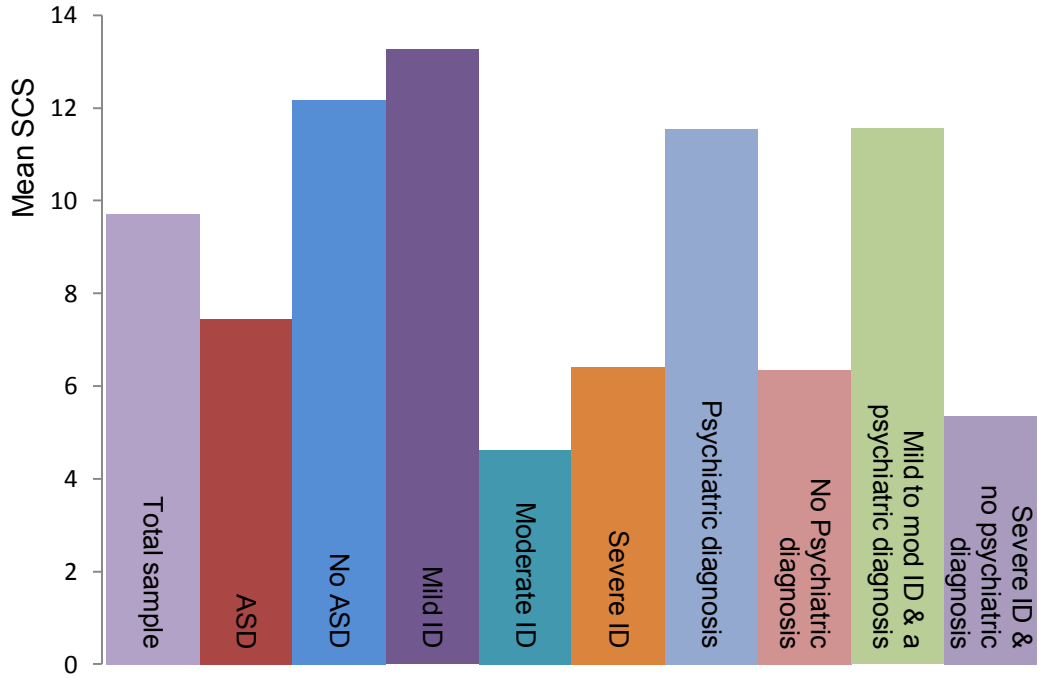
In total, the 98 participants had 1138 contacts with mental health services in the 12 months prior to their informant interview. This is the equivalent of almost one contact a month per participant; although the number of contacts ranged from zero to 106. Service consumption scores for specific subgroups were examined to explore the distribution of service resources among participants. This was to determine whether resources were evenly spread among

participants or whether some groups were consuming disproportionately more than others. It was found that although participants with ASD accounted for 51% of the sample they used only 30% of the services consumed.

Two participants had much higher service use than any others with 106 and 100 contacts compared with the next lowest SCS of 40. Both of these participants were females in the no ASD group who had mild intellectual disability and lived independently. One had depressive disorder and dissociative convulsions while the other participant had bipolar disorder. The majority of their service use was from the mainstream Home Treatment Team and both were on CPA. These participants were removed from the rest of the analyses.

The average number of contacts with mental health services per participant over 12 months is illustrated in Figure 9.5.

Figure 9.5: Mean Service Consumption Scores (SCS) for subgroups of participants



Some groups were consuming higher levels of mental health services; particularly participants without ASD, those with mild intellectual disability and those with a psychiatric disorder.

- Participants with ASD had a significantly lower mean SCS compared to those without ASD (7.4 vs. 12.2; $F(1,95)=4.8$, $p=0.031$).

The participants were divided into high and low service users according to whether they were in the top tertile of scorers (SCS>8). Low-level service users consumed 22% of the services; thus a third of participants consumed 78% of the services.

- Significantly fewer participants with ASD were high-level service users (24%) than those without ASD (44%; $X^2(1)=4.1$, $p=0.043$).

Participants who had been discharged from specialist mental health services at the time of their informant interview (N=9) were removed from these analyses but the results remained significant. However, when those with no service use over the 12 months prior to their informant interview were removed (N=7) the difference in mean SCS between those with and without ASD was no longer significant. Removing those on CPA also made the difference non-significant.

Mental health service consumption score (SCS) was not significantly correlated with total number of needs, total HoNOS-LD score, TPBS on the DBC or total Social functioning score. Nor was SCS significantly correlated with the DBC mental health subscale, problem behaviour subscales or the HoNOS-LD behaviour subscale.

In addition to presence of ASD, SCS was significantly associated with age, severity of intellectual disability, presence of psychiatric disorder and residence (highest among those living independently, lowest among those in residential placements) (see Appendix VI for data).

A linear regression was carried out with these factors entered as independent variables and SCS as the dependent variable. Table 9.32 shows the results.

Table 9.32: Results of the linear regression analysis for service consumption score

	Unstandardised Coefficients			**Standardised coefficients**		
	B	SE (B)	95% CI (B)	β	t	p
Presence/absence of ASD	-4.2	2.2	-8.7 to 0.2	-0.2	-1.9	0.062
Mild intellectual disability	**5.4**	**2.2**	1 to 9.7	**0.26**	**2.4**	**0.016**
Presence of psychiatric disorder	2.8	2.3	-1.7 to 7.3	0.13	1.3	0.212
Age	**-0.2**	**0.1**	**-0.4 to -0.05**	**-0.26**	**-2.6**	**0.012**
Constant	15.2	4.7			3.3	0.002

The model was statistically significant ($F(4,94)=7.7$, $p<0.001$) and accounted for 26% of the variance ($R^2=0.256$). Mild intellectual disability and age were the only significant predictors of mental health service consumption. That is: participants with mild intellectual disability used a significantly greater amount of mental health services than those with moderate/severe intellectual disability and as age increased mental health service use decreased. Once these factors were taken into account, ASD was not significantly associated with mental health service consumption.

In conclusion, participants with and without ASD had been using specialist mental health services for around the same length of time. They saw an intellectual disability psychiatrist on average once every four months regardless of whether they had ASD. Participants with ASD saw a CPN significantly less than those without ASD because they were less likely to be on CPA where fortnightly contact is standard.

Participants with ASD used mental health services less than would be expected given the proportion of the sample that they represented. There was no evidence that they were accessing other types of health service more than those without ASD. However, those with ASD in residential placements had more staff per service user and those attending day centres spent more time there each week than those without ASD.

Psychotropic medication

Most participants (86%) were prescribed at least one psychotropic medication. The proportion of participants prescribed any psychotropic medication was similar for those with (84%) and without (88%) ASD. A considerable number of participants (40%) were prescribed more than one psychotropic medication. Participants with ASD were not more or less likely to be receiving two or more psychotropic medications. The mean number of psychotropic medications (for participants with a prescription) was 1.6 for those with ASD and 1.8 for those without ASD (this difference was not statistically significant).

The type of psychotropic medication prescribed to participants in each group is shown in Table 9.33. The most commonly prescribed psychotropic medication was antipsychotics but many participants were taking anticonvulsants and antidepressants. Other types of medication were rare but some participants were taking benzodiazepines; mainly only when required (PRN) rather than regularly.

Table 9.33: Type of psychotropic medication prescribed to participants

Type of medication	ASD	No ASD
Antipsychotic	34 (68%)	26 (54%)
Anticonvulsant	17 (34%)	14 (29%)
Antidepressant	**6 (12%)**	**20 (42%)**
Anxiolytic	0	1 (2%)
Stimulant (ADHD)	2 (4%)	1 (2%)
Mood stabiliser (Lithium)	1 (2%)	3 (6%)
Benzodiazepine	11 (22%)	4 (8%)
Benzodiazepine PRN	8 (16%)	3 (6%)

See Appendix VI for a list of the medications included in each category.

The only significant difference between those with and without ASD on psychotropic medication prescription overall was that those with ASD were less likely to be on antidepressants than those without ASD ($X^2(1)=11.1$, $p=0.001$). This reflects the earlier finding that participants with ASD were less likely to have a diagnosis of depression than those without ASD.

A considerable proportion of participants (23%) were receiving psychotropic medication despite not having any psychiatric disorder. They were presumably being prescribed medication for challenging behaviour. However, participants with a diagnosis of psychiatric disorder were significantly more likely to be on psychotropic medication compared to those with no psychiatric disorder (95% vs. 68%; $X^2(1)=13.9$, $p<0.001$).

For those with a psychiatric disorder, there was no significant difference between those with and without ASD on whether a participant was receiving any medication. However, among those without a diagnosis of psychiatric disorder, participants with ASD were significantly more likely to be receiving psychotropic medication (78%) than those without ASD (29%; $X^2(1)=6.2$, $p=0.024$[10]).

As such it appears that participants with ASD were more likely to be prescribed medication for challenging behaviour than those without ASD. Table 9.34 shows the proportion of participants with and without a psychiatric diagnosis who were receiving medication.

Table 9.34: Medication prescribed to participants with & without a psychiatric diagnosis

	No psychiatric diagnosis		**Psychiatric diagnosis**	
	ASD N=27	**No ASD** N=7	**ASD** N=23	**No ASD** N=41
No medication	**22%**	**71%**	9%	2%
ADHD			9%	2%
Anticonvulsant	37%	14%	30%	32%
Antidepressant	7%	0%	**17%**	**49%**
Antipsychotic	74%	29%	61%	59%
Anxiolytic			0%	2%
Benzodiazepine	26%	0%	17%	10%
Mood stabiliser (lithium)			4%	7%

[10] P value for Fisher's exact test

It appeared that among participants with no psychiatric disorder, those with ASD were more likely to be receiving antipsychotic medication, benzodiazepines and anticonvulsants than those without ASD but these differences were not statistically significant according to Fisher's exact test. The only significant difference between those with and without ASD among those with a psychiatric disorder was for antidepressants, again reflecting the finding that those with ASD were less likely to have a diagnosis of depression.

There were no significant differences in type of medication between participants with and without ASD among those specific psychiatric diagnoses (see Table 6, Appendix VI). This is likely to be because of the small number of participants in each comparison. The results did not appear to show that participants with ASD were particularly more or less likely to be receiving a treatment appropriate to their diagnosis than those without ASD.

However, these analyses relied on recorded clinical diagnoses which may not accurately reflect the true levels of disorder among participants. Further analyses were carried out to explore whether participants with symptoms of different disorders were receiving appropriate treatment. Items on the HoNOS-LD were used to do this.

There were 53 participants with moderate to very severe scores on either the anxiety or mood items of the HoNOS-LD. Among these participants, those with ASD (N=30) were significantly less likely to be receiving antidepressant or anxiolytic medication than those without ASD (17% vs. 61%; $X^2(1)=11.1$, $p=0.01$). Among participants with psychotic symptoms, there were no differences in the prescription of antipsychotic medication between those with and without ASD.

Whether or not a participant was prescribed psychotropic medication was not significantly associated with total HoNOS-LD score, TPBS on the DBC, total social functioning score or

service consumption score. None of these measures were associated with whether a participant was receiving more than one psychotropic medication. Neither were these were significantly associated with the DBC mental health subscale, problem behaviour subscales or the HoNOS-LD behaviour subscale. These results held regardless of whether participants did or did not have a diagnosis of psychiatric disorder.

The only measures associated with the number of medications prescribed to participants were mental health service consumption score ($r=0.26$, $p=0.018$) and total number of needs ($r=0.23$, $p=0.43$). Therefore, it appeared that those with higher needs and those with more mental health service input were prescribed more psychotropic medications.

However, with regards to specific medications the following results were found (see Appendix VI, table 7 for details):

- Being prescribed an antidepressant was significantly associated with better social functioning and a lower DBC problem behaviour subscale although this association was no longer significant once ASD items were removed from the subscale.
- Being prescribed an antipsychotic was significantly associated with poorer social functioning.
- Being prescribed a benzodiazepine was significantly associated with higher total number of needs, higher total HoNOS-LD score, higher HoNOS-LD behaviour subscale score and poorer social functioning. It was also significantly associated with a higher DBC problem behaviour subscale score although this association was no longer significant once ASD items were removed from the subscale

Being prescribed psychotropic medication was not significantly associated with any other variable apart from presence/absence of psychiatric disorder. However, among those with no

psychiatric disorder there was also a significant association between being prescribed a psychotropic medication and severity of intellectual disability (likelihood increased as severity increased; $X^2(1)=9.3$, p=0.011).

Presence of ASD, presence of psychiatric disorder and severity of intellectual disability were entered into a binary logistic regression (see Table 9.35). Having a psychiatric disorder and having moderate or severe intellectual disability were significantly associated with an increased likelihood of a participant being prescribed psychotropic medication.

Table 9.35: Logistic regression on likelihood of receiving psychotropic medication

	B	SE (B)	p	Exp(B)	95% CI
Presence/absence of ASD	0.56	0.8	0.49	1.8	0.36 to 8.5
Moderate/severe intellectual disability	**1.7**	**0.8**	**0.029**	**5.7**	**1.2 to 27.4**
Presence of psychiatric disorder	**3.4**	**0.9**	**<0.001**	**30.1**	**5.1 to 178.6**
Constant	-0.8	0.8	0.306	0.4	

The binary logistic regression was run again with presence of psychiatric disorder replaced each time with TPBS on the DBC, DBC mental health score, DBC behaviour subscale scores, total HoNOS-LD score, HoNOS-LD behaviour subscale score and social functioning score. None were significant predictors of whether or not a participant was prescribed psychiatric medication.

Participants with globally poor mental health and social functioning

There were 14 participants (14% of the sample) who had globally poor mental health and social functioning:

1) they had mild to moderate problems on the HoNOS-LD (total >22),
2) they met the criteria for psychiatric caseness (TPBS>50)

and 3) they had a less than good rating of social functioning (total score<10).

All but one of these participants had ASD. The participant without ASD who had globally poor mental health and social functioning was the same person who had an SCQ score of 15 (see Table 9.3). Five of those with globally poor mental health and social functioning had mild intellectual disability, three had moderate and six had severe intellectual disability. Five had a diagnosis of psychiatric disorder (psychotic, bipolar and anxiety disorders) and nine did not. Six lived in a residential placement, eight with family and none lived independently.

The mean number of needs that these participants had was 12.4 and 21% of these needs were unmet. The areas in which these individuals had the most unmet need were daytime activities, social relationships, communication, basic education and transport. The items on the DBC that this group scored highly on were: poor sense of danger, poor attention span, impulsivity, arranging objects or routine in strict order and being aloof. The items they scored highly on the HoNOS-LD were occupation, attention, activities in the community, stereotyped behaviour and 'other' behaviours.

A binary logistic regression analysis was carried out to identify which factors were significant predictors of having globally poor mental health and social functioning. The results are shown in Table 9.36. Presence of ASD was the only significant predictor of having globally poor mental health and social functioning with an odds ratio of 11.

Table 9.36: Results of the logistic regression for globally poor mental health & social functioning

	B	SE (B)	p	Exp (B)	**95% CI**
Presence/absence of ASD	**2.4**	**1.1**	**0.03**	**11**	**1.3 to 96.7**
Severe intellectual disability	0.6	0.7	0.423	1.8	0.4 to 7.6
Presence of psychiatric disorder	-0.5	0.7	0.487	0.6	0.1 to 2.5
Constant	-3.5	1.2	0.003	0.03	

Post-hoc analyses

In addition to the main variables used in the analyses, further checks were carried out to check for possible confounding factors. The length of time that participants had been using specialist mental health services for adults with intellectual disability, number of hours of activity, support and day centre hours were not significantly associated with any other measure.

The reliability of the measures was assessed by examining their internal consistency (Cronbach's alpha). Overall, reliability was good (apart from the CANDID which was improved by removing four items). Table 9.37 examines whether the reliability of the measures was different for those with and without ASD.

Table 9.37: Reliability of the measures for participants with & without ASD

	Cronbach's alpha	
	ASD	**No ASD**
SCQ	0.665	0.586
21-item CANDID	0.513	0.652
HoNOS-LD	0.681	0.667
HoNOS-LD behaviour scale	0.553	0.572
DBC	0.786	0.881
DBC mental health subscale	0.733	0.854
DBC behaviour subscale	0.735	0.724
DBC behaviour scale minus ASD items	0.653	0.802
Social functioning scale	0.663	0.487

The internal consistency of the scales did not appear to vary greatly between those with and without ASD. The SCQ, HoNOS-LD and Social functioning scale were slightly more reliable when used with people who have intellectual disability and ASD. The 21-item CANDID, HoNOS-Ld behaviour scale and all of the DBC scales were more reliable for those without ASD. The DBC had the highest level of Cronbach's alpha; it had good internal consistency for those without ASD and acceptable internal consistency for those with ASD (George & Mallery, 2010).

Conclusion

Compared to those without ASD, participants with ASD had a lower level of mental health service use, a higher number of needs, poorer mental health, more problem behaviours and poorer social functioning. However, when other socio-demographic and clinical factors were taken into account the following results were found.

Higher total number of needs (according to the CANDID) was significantly associated with:

- Moderate and severe intellectual disability
- Living with family or in a residential placement

Poorer health and social functioning (as measured by total score on the HoNOS-LD) was significantly associated with:

- Presence of ASD
- Unmet needs and total number of needs
- Moderate and severe intellectual disability

Poorer mental health (as measured by the TPBS on the DBC) was significantly associated with:

- Presence of ASD
- Total number of needs

More problem behaviours (as measured using behavioural items on the DBC) were significantly associated with:

- Presence of ASD
- Total number of needs

Poorer social functioning (as measured by the social functioning scale for adults with developmental disability) was significantly associated with:

- Total number of needs
- Severe intellectual disability
- Not being diagnosed with a psychiatric disorder

Higher levels of mental health service use were significantly associated with:

- Mild intellectual disability
- Younger age

An increased likelihood of being prescribed psychotropic medication was significantly associated with

- Being diagnosed with a psychiatric disorder (OR=30.1, 95% CI: 5.1 to 178.6)
- Moderate and severe intellectual disability (OR=5.7, 95% CI: 1.2 to 27.4)

An increased likelihood of having globally poor mental health and social functioning (defined as total HoNOS-LD score >22, TPBS>50 and social functioning scale score<10) was significantly associated with:

- Presence of ASD (OR=11, 95% CI: 1.3 to 96.7)

Chapter 10: Clinic study

A supplementary study used routinely collected, service-based data. The study aimed to investigate:

- The rate of clinically diagnosed ASD among specialist mental health service users with intellectual disability.
- Whether the participants included in the main study were representative of the wider clinical population from which they were sampled.
- Whether differences in health and social functioning found in the main study replicated differences in the larger clinical sample.

Method of the clinic study

Participants

The clinic study included the entire population of services users on the Mental Health in Intellectual Disability (MHID) caseload during 2010 (see Chapter 7 for a description of this service). All participants had a clinical diagnosis of intellectual disability (according to ICD-10 criteria; WHO, 1992).

Eligibility criteria

The inclusion criteria for the clinic study were that participants were:

1) on the MHID service caseload between January 2010 and January 2011 (see Chapter 7 for the service's eligibility criteria)

and 2) had an mental health record that indicated they were an 'accepted' MHID service user

The additional inclusion criterion for the ASD group was that participants had a clinical diagnosis of ASD documented in their mental health record.

The exclusion criteria for the clinical study were that:

1) a service user's mental health record indicated that subsequent to being accepted they were deemed ineligible to receive MHID services and were due to be discharged

or 2) there was insufficient information available in their mental health record to determine whether an individual had ASD or the severity of their intellectual disability.

The additional exclusion criteria for the group without ASD were that:

1) the terms 'autistic', 'autistic traits', 'autistic features' or 'autistic behaviours' were specifically mentioned in an individual's mental health record

or 2) a service user's mental health record indicated that it was thought they might have ASD but further assessment was required.

Measures

Most of the data collected for the clinical study were routinely recorded socio-demographic and clinical characteristics. All clinical diagnoses were made or confirmed by an intellectual disability psychiatrist using ICD-10 criteria (WHO, 1992). In addition, health and social functioning data were available; the HoNOS-LD is completed by MHID clinicians during outpatient appointments and CPA reviews.

Data collection

Data were obtained from a database known as CRIS (Case Register Interactive Search); developed by the Biomedical Research Centre (BRC) at King's Health Partners (Stewart et al., 2009). It holds anonymised information sourced directly from the electronic Patient Journey System (ePJS) (see chapter 7). CRIS contains the records of over 150,000 past and

present mental health service users from South East London including all those on the MHID service caseload (Chang et al., 2010).

CRIS domains and fields match the tabs and data entry fields in ePJS. In addition to directly entered data, CRIS can search and retrieve text from attachments such as letters, reports, forms, faxes and emails that are routinely uploaded into the correspondence section of ePJS. Where multiple entries have been made, for example several assessments using a specific measure over time, all data for each entry are retrieved. The system is updated daily. CRIS has been used to explore the characteristics of mental health service users (Stewart et al., 2009) and estimate the cause of mortality among people with serious mental illness (Chang et al., 2010).

Ethical approval

The BRC has been granted ethical approval for the use of CRIS as an anonymised database for secondary analysis by the Oxfordshire Research Ethics Committee C (reference 08/H0606/71). The system has also been approved by the South London and Maudsley NHS Foundation Trust Caldicott Guardian and the Trust Executive. An oversight committee led by the BRC Stakeholder Participation scheme reviews all requests to use CRIS. The clinical data study was approved by the CRIS oversight committee in November 2009 (see Appendix II for the CRIS approval).

Procedure

The CRIS searches, data extraction and analyses were carried out between January 2010 and March 2011. The first search of CRIS was carried out in January 2010 and included service users from Lambeth, Lewisham and Southwark. A subsequent search carried out in January 2011 included service users from Croydon and new service users added to the other caseloads since the first search.

CRIS search

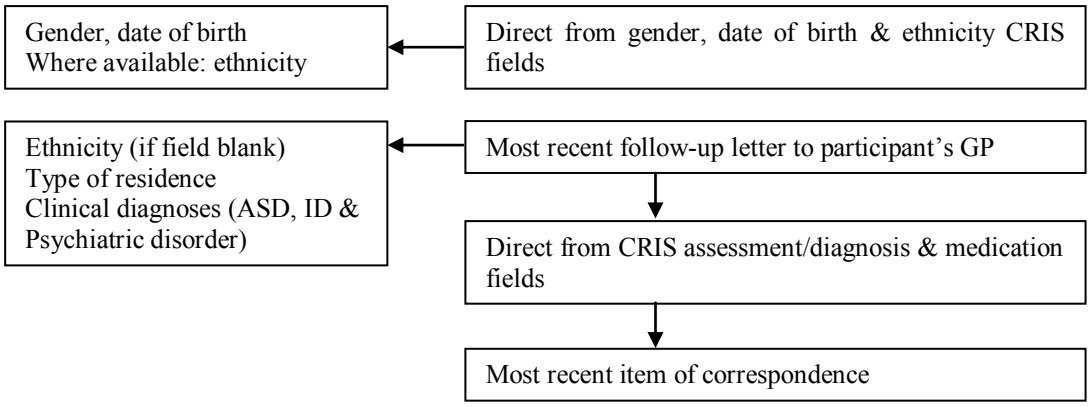
The following strategy was used (See Appendix II for the full search strategy):

Find: all 'active' service users on the MHID caseload

Retrieve: BRC-ID[1], date of birth[1], gender[1], ethnicity, ICD-10 diagnoses[2], correspondence for 2009 and 2010 and all HoNOS-LD scores.

The search results were exported from CRIS into MS Excel spreadsheets. Data were systematically extracted from the downloaded records as shown in Figure 10.1.

Figure 10.1: Sources of data for the clinical study



Identifying participants with ASD

The diagnosis and correspondence information for each service user was systematically screened using Excel's find facility for any mention of the words: '*autism'*, '*ASD'*, '*Asperger'*, '*autistic'*, '*pervasive'* and '*PDD'*. Records that contained these terms were further reviewed to determine whether they indicated that the individual had a clinical diagnosis of ASD, had autistic traits, features or behaviours, were suspected of having an ASD or,

[1] These data are present for all individuals on ePJS/CRIS, other fields are optional and depend on clinicians entering and updating the information.
[2] See Chapter 7 for more details on how this information is recorded.

alternatively, whether any of the terms used were not relevant to the service user themselves or stated they did not have ASD. If there was clinical diagnostic information in a participant's records but no mention of any of the above terms it was assumed that they did not have a clinical diagnosis of ASD or any recognised autistic traits/features/behaviours.

Following this screening participants were put into three groups:

1) Documented clinical diagnosis of ASD (ASD group)
2) No diagnosis or mention of ASD (no ASD group)
3) Presence of autistic traits/features/behaviours or ASD suspected

The third group were participants who were eligible for the study but did not meet the additional criteria for the ASD or no ASD groups. This group will be referred to as having 'ASD traits'.

At the same time as the ASD screen, participants' severity of intellectual disability, type of residence and whether they had an additional psychiatric disorder were extracted. Information in most recent correspondence was cross-checked with past correspondence and diagnosis data to ensure it was consistent across sources.

Analysis

Participants' health and social functioning was measured using the total score on the HoNOS-LD. Exploratory data analyses were carried out to check for homogeneity, normal distribution of continuous variables and outliers. The significance of differences between the groups was tested using analyses of variance (ANOVA) for continuous variables. Chi-squared tests were used for categorical variables except when the cell sizes were small. Fisher's exact test was used when more than 50% of cells had a count less than five.

Results of the clinic study

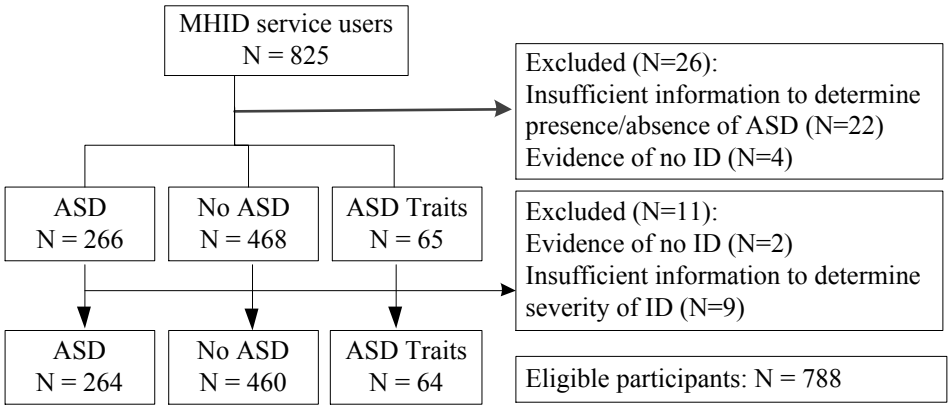
A Case Register Interactive Search (CRIS) identified a total of 825 specialist mental health service users with intellectual disability.

Participants

Following a screen for eligibility, 37 people were excluded from the study because they did not have intellectual disability or because there was not enough information available to determine the severity of their intellectual disability or whether they had ASD (Figure 10.2 shows the flow of participants through the study). Therefore, 788 participants were included in the study and allocated to one of three groups:

1. **ASD**: participants who met the criteria for ASD.
2. **No ASD**: participants who met the criteria for no ASD.
3. **ASD traits**: participants who did not meet the criteria for ASD or no ASD.
   (Individuals who were described as having autistic traits/features/behaviours or who were thought to have ASD but had not received a clinical diagnosis)

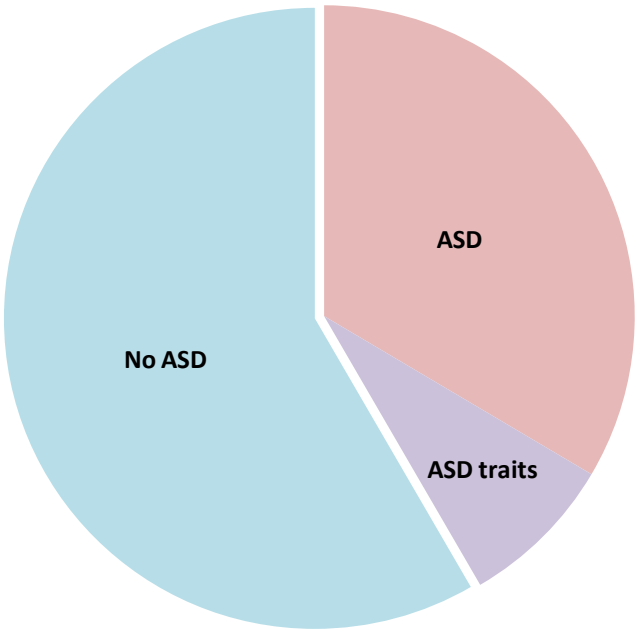
Figure 10.2: Flow of participants through the clinic study



There were 264 participants with a clinical diagnosis of ASD (33.5%), 460 participants with no ASD (58.4%) and 64 participants with ASD traits (8.1%) (see Figure 10.3 below).

Therefore, there was evidence of a clinical diagnosis of ASD (according to ICD-10 criteria) or that an intellectual disability psychiatrist had identified features suggestive of ASD for almost 42% of the 788 participants.

Figure 10.3: Rates of ASD and ASD traits among the 788 included participants



It was not clear why participants with ASD traits had not received a clinical diagnosis. They appeared to be individuals who were awaiting further assessment and participants who had not been formally diagnosed because their symptoms did not reach diagnostic criteria. Participants with ASD traits were a difficult to define and heterogeneous group. Therefore, they were taken out of the dataset and analysed separately (see Chapter 11). The rest of the analyses in this chapter only included participants with or without a clinical diagnosis of ASD (N=724).

Participant characteristics

Table 10.1 shows the characteristics of the 724 included participants. An ANOVA and Chi-squared tests were carried out to investigate differences between the groups with and without ASD.

Table 10.1: Characteristics of the 724 participants with and without ASD

		ASD N = 264	No ASD N = 460	
Age	Mean years (SD)	37.7 (13)	46.9 (14.1)	**F(1,723)=76.4, p<0.001**
Gender	Males	206 (78%)	241 (52%)	**χ^2(1)=46.68, p<0.001**
	Females	58 (22%)	219 (48%)	
Ethnicity	Afro-Caribbean	84 (32%)	100 (22%)	**χ^2(3)=11.31, p=0.01**
	Asian	16 (6%)	20 (4%)	
	White	150 (57%)	306 (67%)	
	Unclear or other	14 (5.3%)	34 (7.4%)	
Type of Residence[+]	Family	92 (35%)	99 (22%)	**χ^2(3)=43.16, p<0.001**
	Independently	8 (3%)	86 (19%)	
	Residential	156 (60%)	259 (57%)	
	Other*	6 (2.3%)	10 (2%)	

[+] Information unavailable for 2 people with ASD and 6 people with no ASD. * Includes inpatient units, secure units, hostels, prison and participants who were homeless

There were significant differences between participants with and without a clinical diagnosis of ASD on all extracted socio-demographic variables:

- Participants with ASD were younger than those with no ASD.
- Participants with ASD were more likely to be male than those with no ASD.
- Participants with ASD were more likely to be Afro-Caribbean ($\chi^2(1)=9, p= 0.003$) and less likely to be White ($\chi^2(1)=6.8, p=0.009$) than those with no ASD.
- Participants with ASD were more likely to live with family (χ^2 $(1)=15.3$, $p<0.001$) and less likely to live independently ($\chi^2(1)=36.4, p<0.001$) than those with no ASD.

Table 10.2 shows the clinical characteristics of the participants and the prevalence of ASD among those with different severities of intellectual disability and with/without a diagnosis of psychiatric disorder.

Most participants (55%) had mild intellectual disability; the rate of ASD among this group was 22%. Fewer participants had moderate and fewer still had severe intellectual disability but the rate of ASD increased with each level of severity.

Table 10.2: Clinical characteristics of the participants

		Total N=724	Number (% with ASD)
Severity of ID	Mild	400 (55%)	87 (22%)
	Moderate	208 (29%)	95 (46%)
	Severe	116 (16%)	82 (71%)
Psychiatric Disorder[+]	Present	520 (73%)	137 (26%)
	Absent	193 (27%)	122 (63%)

[+]Information was unavailable or unclear for 11 participants.

Participants with ASD were less likely to have mild intellectual disability (33% vs. 68%; $\chi^2(1)=83.5$, $p<0.001$), more likely to have moderate intellectual disability (36% vs. 25%; $\chi^2(1)=10.7$, $p=0.001$) and more likely to have severe intellectual disability (31% vs. 7%; $\chi^2(1)=69.8$, $p<0.001$) than those without ASD.

The rate of ASD was higher among those without a diagnosis of psychiatric disorder (63%) than it was among those with a disorder (26%).

- Participants with ASD were less likely to have an additional psychiatric disorder than those without ASD (53% vs. 84%; $\chi^2(2)=82.7$, $p<0.000$).

Pattern of psychiatric disorder

Table 10.3 shows the pattern of diagnoses among the 520 participants who had a psychiatric disorder (i.e. participants who did not have a psychiatric diagnosis or had no information on presence/absence of psychiatric disorder were excluded).

Table 10.3: Pattern of disorders among participants with a psychiatric diagnosis

	ASD (N=137)	No ASD (N=383)	
ADHD	**6.6%**	**2.1%**	**$\chi^2(1)=6.4$, p=0.011**
Anxiety disorder	**13.1%**	**5.5%**	**$\chi^2(1)=8.5$, p=0.004**
Bipolar disorder	15.3%	11.7%	$\chi^2(1)=1.2$, p=0.28
Dementia	**0.7%**	**6%**	**$\chi^2(1)=6.4$, p=0.012**
Depressive disorder	18.2%	20.6%	$\chi^2(1)=0.3$, p=0.55
Personality disorder	**0**	**5%**	**$\chi^2(1)=7.1$, p=0.008**
Psychotic disorder	35.8%	43.3%	$\chi^2(1)=2.2$, p=0.137
Other disorders*	10.2%	5.7%	$\chi^2(1)=7.8$, p=0.005

*included mixed anxiety & depression, adjustment disorder & gender identity disorder. See Appendix III for a list of the disorders included in each category.

Among participants with a psychiatric disorder, there was an overall statistically significant difference between the groups ($\chi 2(7)=32.6$, $p<0.001$).

- Among participants diagnosed with a psychiatric disorder, those with ASD were more likely to have been diagnosed with anxiety than those with no ASD.
- Among participants diagnosed with a psychiatric disorder, those with ASD were more likely to have been diagnosed with ADHD than those with no ASD.
- Among participants diagnosed with a psychiatric disorder, those with ASD were less likely to have been diagnosed with dementia and personality disorder than those with no ASD.

These findings were different from the main study in which there were significant differences between the groups on depression. Two factors could account for this: 1) the distribution of diagnoses among the sample of participants recruited into the main study was different to the clinic study sample and/or 2) the proportion of psychiatric diagnoses changed when participants' ASD diagnoses were assessed and those who did not meet the study criteria were excluded from the main study.

It appears that both these suggestions are true to a certain extent. The proportion of participants with a psychiatric diagnosis was slightly lower among the 129 participants recruited into main study than it was in the clinical study. There were only two people with ASD and depression recruited and one of these was excluded from the ASD group leading to the difference between those with and without ASD. In addition, a high proportion of those who were excluded from the no ASD group of the main had psychotic disorder (56%) so the relative proportions of the different psychiatric diagnoses changed.

In conclusion, participants with ASD were significantly different from those without ASD on a number of socio-demographic and clinical characteristics. Individuals with ASD appear to form a distinct group among specialist mental health service users with intellectual disability. Although this could indicate a true difference in the prevalence of ASD among specific groups it could also be associated with disparities in referral to specialist mental health in intellectual disability services, access to other services and recognition. It is likely that many of the differences with regards to participants' clinical profiles reflect the difficulties of assessing adults with intellectual disability for ASD and mental health problems, particularly as severity of intellectual disability increases. Nonetheless, it is these clinical profiles that would have formed the basis of treatment decisions for this sample.

Health and social functioning

There were HoNOS-LD scores available for 618 participants; 78% of the sample. Of these 618 participants, 32.5% had a clinical diagnosis of ASD, 59.1% had no ASD 8.4% had ASD traits. A slightly lower proportion of service users with ASD (76.1%) had been assessed using the HoNOS-LD compared to those no ASD (79.3%) and those with ASD traits (81.3%) but these differences were not significant.

Significantly fewer male participants (76%) had a HoNOS-LD score compared with 82% of female participants ($\chi^2(1)=4.1, p=0.043$). Participants with a HoNOS-LD score were significantly younger (mean=42.4 years old) than those without a score (mean=45; $F(1,787)=4.5$, $p=0.034$). Indicating that perhaps older, male participants might be under-represented among the sample with a HoNOS-LD assessment. Apart from this there were no statistically significant differences between those who had and had not been assessed using the HoNOS-LD according to ethnicity, severity of intellectual disability, presence/absence of psychiatric disorder or type of residence. As such, there did not appear to be any considerable selection bias.

The HoNOS-LD analyses included only those with a clinical diagnosis of ASD or no ASD (n=566). Data for participants with ASD traits are reported in Chapter 11. Some items in the HoNOS-LD were not completed resulting in missing data. There were five participants with more than four missing item scores. These participants were excluded from the analyses. Exploratory data analyses showed that the HoNOS-LD data was sufficiently normally distributed with acceptable distribution of outliers and equality of variance between the groups with and without ASD. Therefore, it was considered that the assumptions for parametric testing were met.

Total HoNOS-LD scores

Of the 561 participants included in the HoNOS-LD analyses, 200 had a clinical diagnosis of ASD (35.65%) and 361 had no ASD (64.35%). The internal consistency of the HoNOS-LD measured using Cronbach's alpha was 0.84.

The mean total HoNOS-LD score for participants with a clinical diagnosis of ASD was 18.2 (SD=9.5) compared with 13 (SD=9.1) for those without ASD. This difference of around five 'points' was statistically significant ($F(1,560)=40.3$, $p<0.001$). Thus, as in the main study, participants with ASD appeared to have lower health and social functioning than those without ASD.

There were no a significant associations between age, gender, ethnicity and total HoNOS-LD score. Mean HoNOS-LD score was significantly lower for those living independently but similar for those in the other categories. As in the main study, mean total HoNOS-LD scores increased significantly with severity of intellectual disability ($F(1,560)=57$,$p<0.001$). Participants without an additional diagnosis of psychiatric disorder had significantly higher HoNOS-LD scores than those with a diagnosis of psychiatric disorder ($F(1,560)=19$, $p<0.001$).

HoNOS-LD subscales

Using the item groupings identified by Tsakanikos et al. (In preparation), subscale scores were calculated and compared between those with and without a clinical diagnosis of ASD. Table 10.4 shows the mean scores for participants with and without ASD on the three HoNOS-LD subscales.

Table 10.4: Mean scores (& SD) on the HoNOS-LD subscales

	ASD N=200	**No ASD N=361**	
Neuro-cognitive functioning	5.6 (4)	3.2 (3.4)	$F(1,560)=56.2$, $p<0.001$
Mental/behavioural problems	5.7 (4.4)	3.8 (3.6)	$F(1,560)=29.1$, $p<0.001$
Health/social functioning	7 (4.1)	6 (4.7)	$F(1,560)=5.68$, $p=0.017$

The results were similar to those found in the main study and appeared to show that participants with ASD have lower functioning in all three domains of the HoNOS-LD than those without ASD.

HoNOS-LD ASD subscale

It has been suggested that adults with ASD would be expected to score high on items relating to attention, communication and relationship problems. Therefore analyses of individual item scores were carried out. This was to determine whether there were any particular items that might have influenced the results of the total score analyses.

Participants with ASD had a higher mean score than those without ASD on 14 items of the HoNOS-LD. An investigation was carried out to identify which five of these 14 items had the greatest difference in mean scores between those with and without ASD. These were found to be: Expressive communication, Stereotyped behaviour, Receptive communication, Attention/concentration and Anxiety. These items appear to be clinically meaningful with regards to the characteristics of people with ASD. It may be important to take them into account when looking at differences in the total HoNOS-LD scores between those with and

without ASD. They may provide a useful indicator that an individual who does not have a clinical diagnosis should be assessed for ASD. These items were said to form an ASD subscale within the HoNOS-LD.

The mean total score for these five items was 6.4 (SD: 3.8) for participants with a clinical diagnosis of ASD and 3.2 (SD: 2.9) for those without ASD ($F(1,560)=129.9$, $p<0.000$). This ASD subscale had acceptable internal consistency (Cronbach's alpha was 0.74 for participants with ASD and 0.81 for those without ASD).

When these items were removed from the total HoNOS-LD scores, the mean total scores for the remaining 17 items were 11.8 (SD: 6.7) for participants with ASD and 9.9 (SD: 7) for those without ASD ($F(1, 560)=9.8$, $p=0.002$). Thus, a significant difference remained even when items that appear to be ASD-specific were removed; although the magnitude of the difference was reduced to around two points.

Further analyses of data from the main study were carried out to determine whether differences between participants on the HoNOS-LD remained when these ASD-type items were removed. The results are shown in Table 10.5.

Table 10.5: HoNOS-LD results for main study participants with ASD items removed

	ASD N=50	**No ASD N=48**	
HoNOS-LD ASD subscale	**6.4 (3)**	**2.4 (1.6)**	$F(1,97)=69.3$, $p<0.001$
HoNOS-LD Total score excluding ASD items	**13.4 (6.8)**	**8.6 (5.6)**	$F(1,97)=14.4$, $p<0.001$

Participants with ASD in the main study scored higher on the ASD subscale and a significant difference between those with and without ASD remained when these items were removed from the total HoNOS-LD score.

Among the sample from the main study, the internal consistency of the ASD subscale was questionable (0.64) but ASD score was significantly correlated with total SCQ score ($r=0.72$, $p<0.001$). Cronbach's alpha for the total HoNOS-LD score when the ASD items were removed was 0.7 which is acceptable.

Quality of the anonymised clinical data

The screening and extraction of the data for the clinical study using CRIS was very successful with few missing data. It was possible to ascertain both severity of intellectual disability and presence/absence of a clinical diagnosis of ASD for 88% of the entire sample of 825 participants. For a further 8% it was possible to determine severity of intellectual disability and presence of ASD traits. Only 4.5% of the sample had to be excluded due to insufficient information. The amount of missing data for the 788 included participants was low. Data on gender, ethnicity and age were available for all participants. There were data on type of residence for 99% of participants and presence/absence of psychiatric disorder for 98%.

Most of the data were sourced from reports and correspondence to participants' GPs. If data had been extracted directly from the fields for ethnicity, type of residence and ICD-10 diagnoses there would have been much less data and the results might have been considerably different. For example, the prevalence of ASD if taken straight from the ICD-10 diagnoses fields would have been just 16% and none of the participants with ASD traits would have been identified.

Conclusion

In this descriptive study of routinely collected data from an entire clinic sample of specialist mental health service users with intellectual disability, individuals with a clinical diagnosis of ASD formed a distinct group with significantly different characteristics and health and social functioning compared to those without ASD.

The rate of clinically diagnosed ASD was 33.5%. A further 8% of participants were described as having ASD traits but had not been given a formal diagnosis. The clinic study provided further evidence that specialist mental health services users with intellectual disability and ASD have poorer health and social functioning than those without ASD.

Participants with and without ASD were broadly similar in each of the main and clinic study with regards to:

- Age
- Ratio of males to females
- Distribution of ethnic groups
- Type of residence (although a higher proportion of participants without ASD in the main study lived independently than did in the clinic study).

Among participants with ASD, the main study included a slightly higher proportion of individuals with mild intellectual disability and a lower proportion of those with a diagnosis of psychiatric disorder than was found in the wider clinic population. The pattern of differences between participants with and without a clinical diagnosis of ASD was broadly similar to that found in the main study. The pattern of significant differences was the same for each study with the exception of ethnicity.

Chapter 11: Participants with ASD traits/behaviours

Chapter 9 tested the main hypotheses for the thesis. Chapter 10 compared results from the main study with data from the wider clinic population. However, the studies produced some new questions. These concern the individuals who were excluded from the studies: those who did not meet the study criteria for ASD or no ASD.

Main study

As reported in Chapter 9, 28 participants who had no clinical diagnosis or mention of ASD in their mental health record were excluded from the main study because they exceeded the threshold for ASD on the ADOS or appeared to meet ICD-10 criteria for ASD. This group will be referred to as having ASD behaviours.

The excluded participants with ASD behaviours had significantly higher scores on the SCQ (mean=13.6) than those without ASD included in the study (mean=5.5; $F(1,69)=61.8$, $p<0.001$). They were also significant more likely to have an SCQ score above 15; the cut-off point for ASD (46% vs. 2%; $X^2(1)=20.8$, $p<0.001$). The excluded group with ASD behaviours had significantly lower SCQ scores than those with ASD (mean=16.2; $F(1,74)=4.5$, $p=0.038$). This could indicate that there is a threshold of ASD behaviours below which individuals with intellectual disability tend not to receive an ASD diagnosis or whose behaviours go undocumented as possibly being due to ASD. However there were many people in the ASD group who had low SCQ scores so this does not appear to be the case.

The characteristics of participants with ASD behaviours compared with those included in the study are shown in Table 11.1. Participants with ASD behaviours[b] appeared to be similar to those with ASD[a], except that they were significantly older. There were no other significant differences between the excluded group and participants with ASD.

Table 11.1: Characteristics of participants excluded from the 'no ASD' group of the main study

		ASD[a] N=50	ASD behaviours[b] N=28	No ASD[c] N=48	Significant differences
Age	Mean years (SD) Range	36.4 (12.4) 18 to 68	42.8 (12.6) 20 to 64	43.7 (11.6) 20 to 63	a & b ($F(1,77)=4.61$, $p=0.035$)
Severity of ID	Mild Moderate Severe	20 (40%) 14 (28%) 16 (32%)	8 (29%) 6 (21%) 14 (50%)	35 (73%) 12 (25%) 1 (2%)	b & c ($\chi^2(2)=26.8$, $p<0.001$)
Gender	Males Females	40 (80%) 10 (20%)	23 (82%) 5 (18%)	29 (60%) 19 (40%)	b & c ($\chi^2(1)=3.9$, $p=0.049$)
Ethnicity	Afro-Caribbean Asian White Unclear/other	19 (38%) 2 (4%) 27 (54%) 2 (4%)	9 (32%) 2 (7%) 17 (61%) 0	15 (31%) 1 (2%) 30 (63%) 2 (4%)	None
Type of residence	With family Residential Independently	21 (42%) 27 (54%) 2 (4%)	5 (18%) 22 (78%) 1 (4%)	11 (23%) 23 (48%) 14 (29%)	b & c ($\chi^2(3)=11.04$, $p=0.012$)
Psychiatric disorder	Present Absent	23 (46%) 27 (54%)	18 (64%) 10 (36%)	41 (85%) 7 (15%)	b & c ($\chi^2(1)=4.55$, $p=0.033$)

The clinical profile of those excluded[b] was considerably different from those without ASD[c] who were included in the main study. They were: less likely to have mild and more likely to have severe intellectual disability, more likely to be male, more likely to live in a residential placement, less likely to live independently and less likely to have been diagnosed with a psychiatric disorder.

There were a number of features of the excluded group that may suggest why they did not meet the study criteria for 'no ASD' or why their behaviours have not been recognised as being associated with ASD. A considerable number of those with no clinical diagnosis of ASD had epilepsy (N=19; 25%). The majority of this group (68%) were excluded. All of the participants who had no clinical diagnosis of ASD and were non-verbal were excluded. It is not clear whether this indicates a limitation of using the ADOS with non-verbal adults who have intellectual disability.

When compared to those *with* ASD, the group with ASD behaviours:

- Were more likely to have epilepsy (46% vs. 16%; ($X^2(1)=8.14$, p=0.004).
- Had fewer staff per service user during the day (0.66 vs. 1; F(1,47)=10.5, p=0.002) and fewer staff over 24 hours (1 vs. 1.4; F(1,747)=9.1, p=0.004).
- Were receiving more psychotropic medications (1.8 vs. 1.1; F(1,77)=8.8, p=0.004).
- Had lower total HoNOS-LD scores (15.9 vs. 19.8; F(1,77)=4.2, p=0.044) and Mental health/behavioural subscale scores 6.4 vs. 9.1; F(1,77)=7.6, p=0.007).
- Had lower Total Problem Behaviour Score (TPBS) on the DBC (42.7 vs. 53.7; F(1,74)=9.9, p=0.002).

When compared to those *without* ASD, the group with ASD behaviours:

- Were less likely to have capacity (39% vs. 85%; ($X^2(1)=17.4$, p<0.001).
- Were more like to have epilepsy (46% vs. 13%; ($X^2(1)=10.2$, p=0.001).
- Were less likely to be on CPA (11% vs. 33%; ($X^2(1)=4.5$, p=0.033).
- More likely to be on antipsychotic medication (86% vs. 54%; ($X^2(1)=7.82$, p=0.005).
- Had a higher total number of needs (12.8 vs. 10.7; F(1,71)=8.2, p=0.006) and more met needs (11 vs. 9; F(1,71)=7.2, p=0.009).
- Were more likely to be supervised when in the community (68% vs. 36%; ($X^2(1)=7.1$, p=0.008).
- Had more hours of support per week (18.3 vs. 8.7; F(1,24)=6.4, p=0.019).
- Were more likely to be non-verbal (29% vs. 0%; ($X^2(1)=15.3$, p<0.001).
- Less likely to have ever worked (15% vs. 40%; ($X^2(1)=5.04$, p=0.025).
- Less likely to currently work (7% vs. 29%; ($X^2(1)=4.7$, p=0.03).
- Had higher total HoNOS-LD scores (15.9 vs. 11; F(1,75)=9.4, p=0.003).

- Had higher Neurocognitive HoNOS-LD subscale scores (4 vs. 1.8; $F(1,75)=19.8$, $p<0.001$) and higher Mental health/behavioural HoNOS-LD subscale scores 6.4 vs. 4.5; $F(1,75)=4.9$, $p=0.029$).
- Had higher HoNOS-LD ASD subscale scores (5 vs. 2.4; $F(1,75)=27.7$, $p<0.001$).
- Had higher TPBS on the DBC (42.7 vs. 29.2; $F(1,69)=9.9$, $p<0.001$).

To summarise, participants with ASD behaviours excluded from the main study had a socio-demographic and clinical profile that was similar to those with a confirmed diagnosis of ASD. This group's mental health and social functioning seemed to fall in the middle of those with and without ASD. Importantly, the only variable on which those with ASD and ASD behaviours significantly differed was age. Perhaps indicating that the likelihood of having undiagnosed ASD increases with age. This could help explain why studies consistently find that specialist mental health service users with intellectual disability and ASD are younger than those without ASD.

Clinic study

A small but significant number of participants in the clinic study were described as having ASD traits, features or behaviours but had not received a clinical diagnosis. These participants were removed from the main analyses in order to simplify what was already a large and complex sample. Table 11.2 shows the characteristics of the 64 participants with ASD traits and which group they significantly differed from.

Ethnicity was the only variable for which participants with ASD traits were not significantly different from either those with or without a clinical diagnosis of ASD.

Table 11.2: Characteristics of participants with ASD traits in the clinical study

		ASD traits N = 64	Significant differences
Age	Mean years (SD)	35.97 (14.24)	Significantly younger than group with **no ASD**
Gender	Males	38 (59.4%)	Significantly fewer males than the group with **ASD**
	Females	26 (40.6%)	
Ethnicity	Afro-Caribbean	20 (31.3%)	
	Asian	0	
	White	38 (59.4%)	
	Unclear or other	6 (9.4%)	
Type of Residence	Family	23 (35.9%)	Significantly more were living independently compared to group with **ASD**
	Independently	8 (12.5%)	
	Residential	31 (48.4%)	
	Other	2 (3.1%)	
Severity of ID	Mild	38 (59.4%)	Significantly more likely to have mild ID and less likely to have severe ID than group with **ASD**
	Moderate	20 (31.3%)	
	Severe	6 (9.4%)	
Psychiatric Disorder	Present	41 (64.1%)	Significantly less likely to have a diagnosis than group with **no ASD**
	Absent	23 (35.9%)	

Participants with ASD traits were more like those with ASD for age, presence of psychiatric disorder and specific psychiatric diagnosis. Participants with ASD traits were more like those without ASD for gender, type of residence and severity of intellectual disability. Participants with ASD traits did not appear to be consistently similar to either those with or without a clinical diagnosis of ASD. They tended to fall somewhere in between the two groups.

This reflects the heterogeneity among those with ASD traits. It could be assumed that if this group were formally assessed for ASD a significant proportion would receive a diagnosis. The main study provided evidence if all the participants without ASD in the clinical study were assessed it is likely that some would have traits suggestive of ASD, particularly among those with severe intellectual disability.

Of the 64 participants with ASD traits, 52 had a HoNOS-LD assessment. The results of comparisons between the group with ASD traits and those with and without a clinical diagnosis of ASD were:

- Participants with ASD traits had a significantly lower mean total HoNOS-LD score compared to those with ASD (15.2 vs. 18.3, F(1, 252)=4.2, p=0.041).
- Participants with ASD traits had significantly lower mean scores than those with ASD on the Neuro-cognitive functioning (3.7 vs. 5.6, F(1, 252)=10.5, p=0.001) and ASD subscales (4.3 vs. 6.4, F(1, 252)=14.1, p<0.001).
- Participants with ASD traits had a higher mean total HoNOS-LD score than to those without ASD but the difference was not statistically significant.
- Participants with ASD traits had significantly higher mean scores than those without ASD on the Mental/behavioural HoNOS-LD (mean=3.8, F(1,412)= 10.2, p=0.002) and ASD subscales (mean=3.2, F(1,412)=6.7, p=0.01).

In conclusion, the participants with ASD traits seemed to occupy the middle ground between those with and without a clinical diagnosis of ASD on a range of socio-demographic and clinical variables including health and social functioning.

Conclusion

Rates based on clinical diagnoses are likely to underestimate the number of specialist mental health service users with intellectual disability who have ASD. In some cases the person's ASD traits may have been acknowledged. However, there is a group whose behaviour is consistent with a diagnosis of ASD (according to standardised diagnostic assessment) who have no mention of ASD in their mental health record. These service users have a similar socio-demographic and clinical profile to those with ASD, except that they are older.

Chapter 12: Discussion and conclusion

The aim of the thesis was to determine whether participants with ASD from a specialist mental health service for adults with intellectual disability have a different clinical and social functioning profile compared to those without ASD. That is:

- Do those with ASD have distinct characteristics or needs?
- Is their pattern of service use different?
- Are these factors and/or the presence of ASD significantly associated with mental health, behaviour and social functioning?

Summary of findings

Hypothesis one (participants with ASD will have more needs) - **partially accepted:**
Participants with ASD had a significantly greater number of needs (as measured by the CANDID) than those without ASD. However, there was no significant difference between those with and without ASD on number of unmet needs or the proportion of their needs that were unmet. When severity of intellectual disability and type of residence were taken into account ASD was not a significant predictor of participants' total number of needs.

Hypothesis two (participants with ASD will have poorer health & social functioning) - **accepted:** Participants with ASD had significantly poorer health and social functioning than those without ASD (as measured by the HoNOS-LD). Health and social functioning was also independently associated with severity of intellectual disability and needs.

Hypothesis three (participants with ASD will have poorer mental health) - **accepted:**

Participants with ASD had significantly poorer mental health than those without ASD (as measured by total score on the DBC). Mental health was also independently associated with total number of needs.

Hypothesis four (participants with ASD will have poorer behaviour) - **accepted:**

Participants with ASD had significantly higher levels of problem behaviour than those without ASD (as measured by a behaviour subscale of the DBC). Problem behaviour was also independently associated with total number of needs.

Hypothesis five (participants with ASD will have poorer social functioning) - **partially accepted:**

Participants with ASD had significantly poorer social functioning than those without ASD (as measured by a social functioning scale for adults with developmental disability). However, when severity of intellectual disability, absence of a psychiatric disorder and needs were taken into account, ASD was not a significant predictor of social functioning.

Hypothesis six (participants with ASD will use more mental health services) - **rejected:**

Participants with ASD had significantly lower levels of mental health service use than those without ASD. However when severity of intellectual disability and age were taken into account, ASD was not a significant predictor of mental health service consumption score.

Hypothesis seven (participants with ASD will use more psychotropic medication) - **rejected:**

There was no significant difference in the rate of psychotropic medication or number of psychotropic medications prescribed to participants with and without ASD. Whether or not a participant was prescribed a psychotropic medication was associated with severity of intellectual disability and presence of psychiatric disorder.

Hypothesis eight (mental health and social functioning will be associated with unmet needs, service use & intellectual disability severity - **partially accepted:**

Total HoNOS-LD scores were significantly associated with unmet needs but total number of needs was a significant predictor of mental health and social functioning according to the DBC and social functioning scale.

Measures of mental health, behaviour and social functioning were not significantly associated with mental health service consumption score.

Mental health service use, psychotropic medication, needs and social functioning, were significantly associated with severity of intellectual disability. Mental health (according to a mental health subscale of the DBC) was not associated with severity of intellectual disability.

Discussion

The thesis successfully tested a number of hypotheses on the impact of ASD on specialist mental health service users with intellectual disability.

Clinical and social implications of the findings

A striking feature of the results was that mental health, problem behaviour, health and social functioning, mental health service use, medication use and needs tended to be significantly associated with clinical rather than socio-demographic factors. There was no evidence to suggest that these measures were affected by gender or ethnicity. Age and type of residence were significantly associated with some variables but usually not once other factors had been taken into account (apart from needs and mental health service use).

Furthermore, perhaps with the exception of needs, these significant predictors are not characteristics that can be changed or improved. It appears that services (and research) should

focus on ways of improving provision to specific subgroups of people with intellectual disability who have mental health and behavioural problems. These subgroups should defined by clinical characteristics such as: additional comorbidities (e.g. ASD), severity of intellectual disability and presence/absence of psychiatric disorder.

The study provided evidence that among specialist mental health service users with intellectual disability there appears to be:

- High levels of undiagnosed ASD.
- Undiagnosed mental health problems.
- High rates of psychotropic medication in the absence of psychiatric disorder.
- Inequalities in service provision and psychotropic medication use.

The recent NICE guidelines make it clear that having unrecognised ASD, untreated mental health problems, inappropriately managed behaviour problems or receiving inadequate services can have considerable repercussions for adults on the autism spectrum and those around them (NICE, 2012). For individuals with intellectual disability, these circumstances may lead to increased difficulties with trying to live more independently, finding or maintaining employment, forming relationships and accessing community facilities. Thus leading to increased social exclusion. This study found that participants with intellectual disability and ASD had more problems with these aspects of their lives than those without ASD.

Undiagnosed disorders and ineffective intervention may also increase the risk of an individual causing harm to themselves or others. There are also implications for services; they may end up attempting to manage patients without sufficient resources or expertise, treating individuals for longer than necessary and diverting resources away from other service users.

Further research is needed to establish whether improvements in ASD recognition, problem behaviour and mental health lead to better social functioning. Establishing the most effective ways of identifying and meeting the needs of adults who have intellectual disability, ASD and mental health problems is vital.

There does not appear to be sufficient evidence on which to base the current assumption that specialist intellectual disability services are able to sufficiently recognise, assess and provide effective management of people with low-functioning ASD who have additional mental health needs. More research is needed on current pathways experienced by adults with intellectual disabilities who present to mental health services with symptoms of ASD and how these might be changed in order to improve diagnostic accuracy. Ideally this work would complement the work carried out by the National Audit Office which demonstrated that improved recognition of high-functioning ASD would lead to improved outcomes (Doctors.net.uk, 2008; National Audit Office, 2009a; National Audit Office, 2009b).

The NICE guidelines also make it very clear that challenging behaviour in adults with ASD should be assessed using functional analysis. Furthermore, that psychosocial intervention, based on behavioural principles, should be offered for those with challenging behaviour before considering medication (NICE, 2012). Recommendations state that, when prescribed, antipsychotic medication should be offered in conjunction with a psychosocial intervention. The main study found that 74% of participants with ASD who had no diagnosis of psychiatric disorder were receiving antipsychotic medication. Only 35% of these participants had received behaviour support in the last 12 months.

Specialist mental health services for adults with intellectual disability tend to focus on treating psychiatric disorders (mainly with medication). It may be that a more appropriate care pathway for those who do not have a diagnosis of psychiatric disorder would be a behavioural

service that is more geared towards providing for individuals who have long-term, chronic and persistent problems (Royal College of Psychiatrists, 2001b). However, before individuals are diverted to this service they should receive comprehensive assessment to ensure that they do not have an undiagnosed psychiatric disorder.

Undiagnosed ASD

A significant finding of the study was the apparently high level of undiagnosed ASD among this sample of specialist mental health service users with intellectual disability. The study provided evidence that the routine assessment of ASD using a standardised screening tool would increase the recognition of ASD among specialist mental health services users with intellectual disability (provided this is followed up by a comprehensive diagnostic assessment where appropriate).

National guidelines recommend clear pathways for the recognition, referral and assessment of ASD (Department of Health, 2010b; NICE, 2011; NICE, 2012). However these do not appear to be in place for adults with intellectual disability. That is, it is assumed that referral to a specialist intellectual disability service is sufficient. However, the thesis has demonstrated that even within a specialist mental health service, there are individuals with intellectual disability who have recognised ASD traits but have not been formally diagnosed and many whose ASD behaviours have gone unacknowledged. There was little evidence that the participants in the main study had undergone standardised ASD assessment (e.g. using the ADOS, ADI or DISCO) whilst receiving specialist intellectual disability services or that there was any policy of referral to specialist ASD assessment services.

It is vital that intellectual disability services are able to adequately recognise signs and symptoms of ASD. Regardless of whether this triggers an assessment or referral to a specialist

ASD team, without that initial identification individuals will continue to go undiagnosed and their needs unmet (NICE, 2012). More awareness and training on ASD for people who work with individuals who have intellectual disability is needed. This should be implemented at all levels; from residential staff, general practitioners and social care staff to specialist intellectual disability psychiatrists and nurses (Department of Health, 2010c).

Knowing that an individual has ASD can help those who work with or care for that person to better understand their behaviour. If an individual consistently behaves in a way that is challenging, knowing that they have ASD can provide a great deal of insight into why this might be. Perhaps they do not have enough routine; perhaps they do not understand what is being asked of them; perhaps they experience hypersensitivity and their environment is overwhelming. If it is known that a person has ASD or even just that they have a higher than usual number of ASD symptoms this can improve understanding of their behaviour in terms of impairments in social interaction, communication and the presence of restricted interests.

Undiagnosed mental health problems

There was some evidence from the main study that participants without a diagnosis of psychiatric disorder had high levels of mental health symptomatology; perhaps indicating undiagnosed psychiatric disorder. The DBC items that participants scored most highly on appeared to be related to ADHD despite there being low levels of diagnosed ADHD among the sample. This was particularly the case among participants with ASD. Rates of diagnosed depression were significantly lower among participants with ASD than those without ASD. However, analysis of HoNOS-LD data revealed that a similar proportion in each group had moderate to very severe problems with their mood.

There is a great deal of literature on the difficulties of making a diagnosis of psychiatric

disorder in those with intellectual disability and the importance of carrying out a comprehensive and systematic assessment (e.g. Cooper & Simpson, 2006; Davis et al., 2008; Deb et al., 2001a; Kannabiran & McCarthy, 2009; O'Hara, 2007). A number of instruments have been developed to facilitate this including the DC-LD[1], PAS-ADD[2] and DASH[3] (Mohr & Costello, 2007; Royal College of Psychiatrists, 2001a). However, there is no evidence on whether these tools are being used by clinical services when they assess the mental health of adults with intellectual disability.

By comparison, there is acknowledgement that the diagnostic assessment of ASD requires specialist training and should be assisted by standardised tools (Department of Health, 2010a; NICE, 2011; NICE, 2012). Specialist ASD services spend up to six hours with each individual and their family when carrying out an assessment (Murphy et al., 2011). It is not clear whether, in practice, the same level of rigour is considered when diagnosing mental health problems in adults who have intellectual disability (with or without ASD). The Green Light Toolkit states that assessment should be 'skilled', 'integrated' and 'specialised' but offers no further details (Foundation for People with Learning Disabilities, 2004). Many experts question whether criteria developed for the general population, such as ICD-10 and DSM-IV, are appropriate for adults with developmental disorders (Bradley et al., In press; Einfeld & Aman, 1995). There is evidence that rates of psychiatric disorder appear lower when these criteria are applied (Cooper et al., 2007; Melville et al., 2008).

Few recommendations on assessing mental health problems go as far as those for diagnosing ASD where the use of a standardised instrument is viewed as essential and assessors must demonstrate they have sufficient levels of reliability when using them. Formal methods of

[1] Diagnostic Criteria for adults with Learning Disability (Royal College of Psychiatrists, 2001a).
[2] Psychiatric Assessment Schedule for Adults with Developmental Disorders (Prosser et al., 1998).
[3] Diagnostic Assessment for the Severely Handicapped (Matson, 1995).

evaluating consensus and reliability are not routinely used to develop services' ability to carry out consistent assessment and diagnosis of mental health problems in adults with intellectual disability. A system such as that for the ADOS, where clinicians watch a video of an assessment or read a vignette and compare their formulation with a consensus diagnosis could improve the reliability of clinical assessments.

Intervention and management

The study provided evidence that despite receiving specialist mental health services, many individuals with intellectual disability continue to experience significant mental health and behaviour problems. The length of time that participants had been receiving specialist mental health services for adults with intellectual disability was not associated with mental health, problem behaviour or social functioning. Thus, although the study lacked longitudinal data, there was no evidence to suggest that participants' outcomes improved the longer they received specialist services.

There appeared to be several differences in service provision for those with and without ASD. Participants with ASD had lower levels of mental health service use – despite a higher level of need – and were more likely to be prescribed psychotropic medication if they had no diagnosis of psychiatric disorder than those without ASD.

Whether or not participants were prescribed medication did not appear to be related to the extent of their mental health or behavioural problems. Rather, it was associated with severity of intellectual disability or whether they had been given a diagnosis of psychiatric disorder. Furthermore, among those with no psychiatric diagnosis it was related to whether a person had ASD. Similar findings have emerged from previous studies despite the lack of evidence on using psychotropic medication to treat problem behaviour and concerns about adverse effects (Deb, 2009; de Bildt et al., 2006; Paton et al., 2011).

Inequalities in psychotropic medication use were found when specific symptoms were explored. Participants with ASD who had moderate to very severe symptoms of depression and anxiety were significantly less likely to be receiving antidepressant or anxiolytic medication than those without ASD. Lower levels of diagnosed depression were found among participants with ASD but more people in this group had moderate to very severe symptoms than among those without ASD. As described above, this could reflect an under-diagnosis but also an under-treatment of depression among those with ASD.

The next sections of this chapter critically evaluate the methods and results of the thesis against previous research. The structure largely mirrors the literature review reported in Chapters 2 to 5.

Assessment and diagnosis

ASD assessment

Few studies on adults with intellectual disability have used 'gold standard' diagnostic assessments to reliably determine whether or not participants have ASD (Brugha et al., 2009a; Ecker et al., 2010). As such this study was a rare opportunity to explore the use of these methods in this population. The majority (86%) of participants were assessed using the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989). Those who could not take part in an ADOS assessment had their records reviewed by an expert using ICD-10 criteria for ASD. Agreement between routine clinical diagnoses according to ICD-10 criteria and the standardised assessments of ASD (ADOS or expert review) was significant (Cohen's kappa was 0.54, $p<0.001$). However, there was disagreement between the clinical diagnosis and the result of the ASD assessment for the study for 24% of participants.

Assessment of those with a clinical diagnosis of ASD was fairly consistent; there was disagreement on only three out of 53 participants. However, agreement on participants without a clinical diagnosis was low; there was disparity between the clinical diagnosis and standardised ASD assessment for 28 out of 76 participants. It was not clear whether this was because 1) the ADOS is not suitable or the specificity of the cut-off points of the ADOS algorithm is low for adults with intellectual disability who have mental health problems or 2) there was a high level of undiagnosed ASD among the participants.

It is likely that both these factors contributed to the discrepancy between clinical diagnoses and standardised assessment of ASD. Previous studies have suggested that revised algorithms may improve the psychometric properties of the ADOS for children with low-functioning ASD (Gotham et al., 2007). A recent study found that module 4 of the ADOS was less specific when distinguishing between high-functioning adults with ASD and those with schizophrenia (Bastiaansen et al., 2011). There is evidence that clinical diagnoses of ASD have low reliability especially in people with comorbid intellectual disability and other mental disorders (Murphy et al., 2011). The review of the literature on the prevalence of ASD (Chapter 3) found that rates of ASD tend to be lower in studies that rely on clinical diagnoses.

A further complication of using the ADOS with an adult population is that the modules for non-verbal individuals were designed for children. The responses of the participants may have been different if the materials and presses were more age-appropriate. On the other hand, ADOS codings are based on the participant's social interaction with the assessor and their general behaviour. Therefore, the content is largely irrelevant as long as the administration and coding of the assessments are consistent and adhere to the standard methods that are described in the manual.

Having said that, it is clear that the ADOS is not appropriate for all individuals with intellectual disability. The assessment is not suitable for people with profound intellectual disability, severe physical disabilities or sensory impairment. In children this may not be a barrier to assessment using other measures such as the Autism Diagnostic Interview (ADI; Le Couteur et al., 1989) since there will most likely be an available informant who is able to provide information on the individual's early life and development. With adults this becomes less likely. Older parents may find it difficult to remember details accurately. Many of the participants in the main study had no contact with any family members and the information available on their life before their current residential placement was limited or sometimes non-existent. This means while some ADI items can be administered, the scores which feed into the diagnostic algorithm cannot be calculated since they rely on information about the person's behaviour and development as a child (Lord et al., 1994).

Further research is needed on participants with ASD traits/behaviours to determine whether they have undiagnosed ASD. This should include investigation into whether there might be alternative explanations for their ASD-type behaviours. It has been suggested that ASD traits may result from brain damage associated with intellectual disability rather the presence of ASD per se (Bhaumik et al., 2010). This is particularly the case among those with severe and profound intellectual disability. Among participants excluded from those without ASD in the main study for having ASD traits, there were three participants for whom assessors noted there may be other reasons for their lack of social reciprocity. These included antipsychotic medication, past history of alcohol abuse, severe epilepsy and frontal lobe damage.

More studies are needed on other samples of adults who have intellectual disability (with and without mental health problems) to determine whether the current ADOS algorithms should be revised for this group. The ongoing development of adapted version of modules one and

two of the ADOS for non-verbal adults is much welcomed (Berument et al., 2005; Hus et al., 2011). Though validated using pilot studies these versions have not yet been published.

In addition to the standardised diagnostic assessment, continuous measures of ASD symptoms were used or developed: the Social Communication Questionnaire (SCQ; Berument et al., 1999), a HoNOS-LD ASD subscale and a DBC ASD subscale. The psychometric properties of these scales were assessed against the standardised diagnostic measures.

The SCQ is a well validated screening tool that, in this study, had good reliability and sensitivity compared with the other standardised assessments of ASD. Specificity however was low; therefore while it is likely that adults with intellectual disability scoring 15 or above on the SCQ have ASD, those scoring below 15 would require further assessment. This replicates findings from studies of children with intellectual disability (Witwer & Lecavalier, 2007; NICE, 2011).

The reliability (internal consistency) of the HoNOS-LD and DBC ASD subscales were good. More analyses are needed on these scales which are as yet unvalidated in adult populations with intellectual disability. This includes establishing cut-off scores for optimum specificity and sensitivity and testing on further samples of specialist mental health services users with intellectual disability.

Using items from the HoNOS-LD could help to identify specialist mental health service users with intellectual disability who require further assessment for ASD. This would be of great use to services that already use the full scale as a routine outcome measure. The HoNOS-LD ASD subscale could act as the first stage in a screening process without clinicians having to obtain any additional data to that normally collected. The finding that individuals with ASD

tend to score higher on certain items may also help to inform the way that payment by results will work for adults with intellectual disability. It is anticipated that the current or a revised version of the HoNOS-LD will be used to collate data and categorise individuals into diagnosis-based clusters (Hillier et al., 2010).

There was a great deal of ASD symptomatology among participants who did not have a clinical diagnosis of ASD. But there was also a considerable level among the 48 participants who met the study criteria for 'no ASD'. This group's average SCQ score was 5.5 with a range of zero to 15. The presence of ASD features in those with intellectual disability and overlap in symptoms is well established (Bhaumik et al., 1997). As discussed in the literature review, it makes assessing adults with intellectual disability for ASD, mental health or behavioural problems more of a challenge for researchers and clinicians (Hill & Furniss, 2006). More research is needed on which specific symptoms or features are the best predictors of whether an individual with intellectual disability and mental health problems has ASD (Bhaumik et al., 2010; Bradley et al., 2011a).

Assessment of psychiatric disorders

The study relied on existing clinical diagnoses of psychiatric disorder made by specialist intellectual disability psychiatrists according to ICD-10 criteria. It was not possible to reassess these diagnoses since participants were receiving treatment and in many cases had been doing so for a number of years. Many participants' case records acknowledged that their mental health problem was currently in remission. Therefore a standardised diagnostic assessment would only have revealed whether any participants currently met the criteria for a psychiatric disorder; it would not have been able to validate their existing diagnoses. The high scores achieved by some participants on the DBC (including the depressive and anxiety subscales) and specific HoNOS-LD items may indicate a level of undiagnosed psychiatric disorder.

It is likely that there is not one 'gold standard' diagnostic assessment for all individuals with intellectual disability (Deb et al., 2001a). Many of the tools reviewed in chapter 2 have been specifically developed for adults with severe and profound intellectual disability (e.g. DASH-II); others are only suitable for those with mild to moderate impairment (e.g. PAS-ADD). Many researchers suggest that the assessment of psychiatric disorder among individuals with intellectual disability who have ASD requires measures designed especially for this group (Bradley et al., In press; Helverschou & Martinsen, 2011; Matson & Boisjoli, 2008). However, apart from those for children or adults with severe and profound intellectual disability, few have been developed (Underwood et al., 2011).

Prevalence and comorbidity

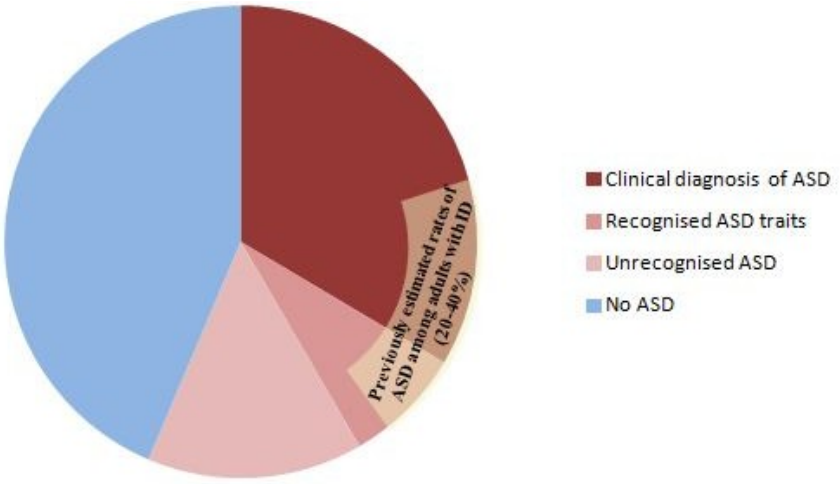
The study was designed to be exploratory and descriptive rather than epidemiological. As such the focus of the results was on participants' mental health and social functioning. However it is possible to use the results to make cautious inferences about the prevalence of ASD among specialist mental health service users with intellectual disability and differences in the comorbidity of mental health problems between those with and without ASD. It is also possible to compare the characteristics and patterns of psychiatric disorder found among participants to those in the general population and among other mental health service users.

Prevalence of ASD

The rate of clinically diagnosed ASD in the clinical study (33.5%) was consistent with previous research on ASD among adults with intellectual disability (Emerson & Baines, 2010). The socio-demographic and clinical profile of those with ASD was also similar to previous studies on adults with intellectual disability with and without mental health problems (Lunsky et al., 2009; McCarthy et al., 2010; Melville et al., 2008; Morgan et al., 2003; Tsakanikos et al., 2006).

The study identified individuals with features consistent with ASD who had not received a diagnosis. If it is assumed that all of those with ASD traits in the clinic study actually had undiagnosed ASD this increases the rate to around 40% which is at the upper limit of most estimates (Matson & Shoemaker, 2009). Furthermore, if the assessments of ASD carried out for the main study were correct in their diagnosis, the estimated rate would be around 56%[1]. This is very high and could indicate that adults with ASD are over-represented among specialist mental health service users with intellectual disability. Figure 12.1 illustrates these estimates.

Figure 12.1: Estimated rate of ASD among specialist mental health service users with intellectual disability based on the thesis results



This could have considerable implications for specialist intellectual disability mental health services where current policy and practice is based on the premise that the majority of service users do not have ASD. Evidence suggesting that more than half of service users have ASD or significant ASD traits could have an impact on commissioning, planning, provision, staffing, training and measurement of outcomes.

[1] See Appendix VII for how this rate was calculated

Characteristics of participants with and without ASD

There was a lower rate of mild intellectual disability among the MHID clinic population compared with most estimates which are around 85% among adults (Bhate & Wilkinson, 2006). Even among participants without ASD only 68% had mild intellectual disability. The rates of moderate and severe intellectual disability were around 2-3 times that usually found in the intellectual disability population (Bhate & Wilkinson, 2006; Maulik et al., 2011). This could explain why the rate of ASD was so high since it is more prevalent among those with more severe intellectual disability. It is likely that, as in the general population, many adults with mild intellectual disability receive primary care treatment for mental health problems and do not require referral to specialist services (Balogh et al., 2008).

As a whole, the proportion of male service users was higher than among the general population and mental health service users of the South London and Maudsley NHS Foundation Trust (SLaM; Stewart et al., 2009). Participants were also younger than these populations. The ratio of males to females was slightly higher than other studies on adults with intellectual disability (Cooper et al., 2007; Emerson & Hatton, 2005b). This could suggest that young males with intellectual disability are more at risk of mental health problems (or more likely to be referred to specialist mental health services). It may also reflect the high number of people with ASD in the sample; who are more likely to be young and male.

The distribution of ethnic groups within the clinic study was similar to the general population and mental health service users in South East London (Stewart et al., 2009). The type of residence that participants with ASD lived in was very similar to that found in an aggregate of data from studies on adults with intellectual disability and ASD. Knapp et al (2009) estimated that among those living in the community: 63% are in supported living/residential placements, 33% live with family and 4% independently.

In conclusion, participants in the study had similar characteristics to other samples of research participants with and without ASD. There was no evidence that they were not representative of the wider population of specialist mental health service users with intellectual disability in the UK.

In common with previous research, the study demonstrated that there is a great deal of heterogeneity among individuals who have intellectual disability and among those with ASD (Carter et al., 1998; Deb et al., 2001a; de Bildt et al., 2004). The differences found between participants with and without ASD did not mean that it was necessarily feasible to characterise particular groups of individuals as more or less likely to have ASD. For example while those with ASD were more likely to be male, most males within the sample did not have ASD. While most participants without ASD had mild or moderate intellectual disability it could not be said that most of those with ASD had severe intellectual disability; there were roughly a third of participants with each severity.

Nonetheless, it appeared that specialist mental health service users with intellectual disability who do not have a diagnosis should be assessed for ASD if they have severe intellectually or no diagnosis of psychiatric disorder. The prevalence of clinically diagnosed ASD was particularly high among these groups (71% and 63% respectfully). The study found that the vast majority of participants with severe intellectual disability had ASD, recognised ASD traits or behaviours consistent with a diagnosis of ASD.

Psychiatric disorder

As described above, rates of ASD among the sample were fairly high suggesting that perhaps individuals with intellectual disability and ASD are at increased risk of psychopathology (or at increased 'risk' of being referred to a specialist mental health service). However, in the

clinic study almost half of those with ASD were receiving specialist mental health services for behavioural problems. The prevalence of ASD among those with a diagnosis of psychiatric disorder was actually about 26%; well within previous estimates. Conversely, the prevalence of ASD among those without a diagnosis of psychiatric disorder was 63%; a very high rate.

This suggests that adults with intellectual disability and ASD are not at increased risk of psychiatric disorder but are at increased risk of challenging behaviour compared to those without ASD. This is consistent with previous studies on mental health problems in adults with ASD and intellectual disability (Melville et al., 2008; McCarthy et al., 2010). The finding that the more severe an individual's intellectual disability and less likely they are to be diagnosed with an additional mental health problem has been found elsewhere (Smith & Matson, 2010).

The study found that participants with ASD were not accessing services as much as those without ASD. There may be strong referral and selection biases influencing the patterns of prevalence found in the study. More population-based studies such as those carried out in Scotland by Cooper et al. (2007; Melville et al., 2008; Smiley et al., 2007; Jones et al., 2008) are needed. However this group's method of recruiting via GPs may also contribute to selection bias. Research needs to recruit from wider, more comprehensive samples, focusing particularly on groups that appear to have least access to services.

The pattern of psychiatric disorders found among the clinical study sample showed that if they are diagnosed at all, participants with ASD appear to have a narrower range of disorders than those without ASD. Both groups are likely to be diagnosed with psychotic disorder but otherwise those with ASD tend to be diagnosed with anxiety disorders where as those without ASD have depression. It is unclear whether this is related to actual differences in the prevalence of these disorders or whether difficulties in assessing psychopathology lead to

clinicians diagnosing fewer disorders in fewer individuals with ASD. The challenges of making a diagnosis could explain why so few of those with ASD had personality disorders and dementia. This highlights the importance of comprehensive assessments by experts with experience of diagnosing mental health problems both in individuals with intellectual disability and those with ASD.

It was possible to compare the pattern of psychiatric disorder found among participants with intellectual disability in the clinical study to a wider population of mental health service users. Stewart et al. (2009) used the Case Register Interactive Search (CRIS) to explore the primary ICD-10 diagnosis assigned to past and present mental health service users in South London. The most common psychiatric diagnoses were mood (affective) disorders (prevalence of 16%), followed by schizophrenia, schizotypal and delusional disorders (10%), substance abuse (9.7%), neurotic disorders (8.9%) and organic mental disorders (8%). A high proportion (30%) of these service users did not have a diagnosis of any ICD-10 mental and behavioural disorder (codes F0-F99; WHO, 1992).

Comparing the clinic study results with this pattern, they would appear to confirm previous findings that adults with intellectual disability are at higher risk of psychotic disorders compared to the general population (Bouras et al., 2003; Deb et al., 2001b; Morgan et al., 2008; Pridding & Tomasoni, 2006). However, it could also mean that adults with intellectual disability and psychotic disorder are more likely to be referred to specialist services than those with other types of mental health problem. Alternatively, it could indicate adults with intellectual disability are more likely to receive a diagnosis of psychotic disorder than adults in the general population. This could be because adults with intellectual disability often have an atypical presentation of disorders such as depression and anxiety (Deb et al., 2001a; Perry et al., 2001).

The rate of attention deficit hyperactivity disorder (ADHD) among participants in the clinical study was surprisingly low (2% overall and 3.4% among those with ASD) compared to previous estimates which range from 14% for those with intellectual disability and up to 45% for those with ASD (NICE, 2011; Ruedrich, 2010). Differentiating features of ADHD from symptoms of other psychiatric disorders, challenging behaviour, ASD and characteristics common among people with intellectual disability is a well-recognised challenge (Bradley et al., 2011b). Along with ASD, ADHD may be a condition that is currently under-recognised and under-diagnosed among specialist mental health service users with intellectual disability.

Some evidence to support this was provided by the main study in which the DBC items that participants scored highest on were: poor attention span, impatience, impulsivity, poor sense of danger and being easily distracted. These appear to be related to ADHD or Hyperkinetic disorder; described in ICD-10 as:

"...a combination of overactive, poorly modulated behaviour with marked inattention and lack of persistent task involvement..." (WHO, 1992; pp. 206).

Needs, service use and intervention

The Autism Strategy for England emphasised the importance of identifying and assessing the needs of adults with ASD within the framework of the Joint Strategic Needs Assessment (JSNA) (Department of Health, 2010b). At an individual level, assessments should be personalised with the person's needs clearly described. Services should be able to effectively recognise respond to those needs (Department of Health, 2010c). However, there appears to be a certain amount of assumption that once it is known that an individual has ASD, their needs have been identified and it is possible to base service and intervention provision around their diagnosis without further individualised assessment of their needs (Bennett et al., 2005).

Needs

It was anticipated that participants with ASD would have greater needs than those without ASD. This was found to be the case; however, there was a lack of difference between the groups on level of unmet need. Participants appeared to have few unmet needs (an average of around two). This is lower than that found in other studies of specialist mental health service users with intellectual disability (Hall et al., 2006). Correspondingly the average level of met need was higher than in previous studies using the CANDID (Martin et al., 2005).

The CANDID had the lowest internal consistency among the measures used in the study. Cronbach's alpha for the full 25-item scale was unacceptably low (George & Mallery, 2010). It was not clear whether this was because the scale is not reliable or whether participants had heterogeneous needs. The internal consistency of the CANDID has not been previously reported so it was not possible to compare the results with other samples.

There was evidence that participants lacked constructive, daytime activity. This was the need that was most often unmet in the CANDID, it was highlighted in the informal assessment of need and Occupation was among the highest scoring HoNOS-LD items. Previous studies on adults with intellectual disability have pointed out the high level of unmet need in this area (Strydom et al., 2005).

A lack of appropriate employment opportunities, education, training, day centres and social clubs can be a particular issue for individuals making the transition from adolescence to adulthood (Royal College of Psychiatrists, 2011). There is good evidence that individuals with intellectual disability and/or ASD find it difficult to adjust to the lack of structure and routine that they receiving from attending school or college (National Audit Office, 2009b; Shattuck et al., 2011). As adults, they also experience high levels of unemployment (Howlin, 2000; Howlin et al., 2004). Participants spent an average of 16 hours a week taking part in

activities; compare this with children and adolescents who are provided with 25 to 35 hours a week of activity in educational settings (Ofsted, 2010).

The number of hours of structured activity that participants were taking part in each week was not significantly associated with mental health although the trend of the relationship between the variables was that as activity increased, mental health improved. However, there was limited evidence that perceived level of activity was associated with mental health (TPBS was significantly correlated with the Occupation item on the HoNOS-LD). This is consistent with previous findings found quality of life is associated with perceived rather than actual levels of support (Renty & Roeyers, 2006). It may indicate that it is not the number of hours of activity that people take part in but whether they feel that they are adequately occupied.

There was no evidence that individuals with physical health needs were more or less likely to have those needs met if they had ASD. It appeared that participants with ASD had fewer health needs than those without ASD; they had fewer recorded physical health problems and were less likely to have 'increased incapacity due to physical problems' according to the HoNOS-LD. This raises the possibility that the health needs of people with intellectual disability and ASD are more likely to go unreported or unrecognised than those without ASD, particularly if they present with mental health or behavioural problems. It is known that there is an under-reporting of physical disorders among people with ASD (NICE, 2012).

Service use

Despite adults with ASD having an increased risk of developing mental health problems there is evidence they do not always have access to appropriate services (Higgins, 2009). A survey of adults with ASD in the UK found no evidence that they had increased mental health service use compared with the general population (Brugha et al., 2009b). The hypothesis on service

use assumed that once an individual with intellectual disability, ASD and mental health problems was receiving a specialist service their high levels of needs would mean that they had a high level of service consumption. This was not supported by the data.

Participants with ASD used proportionally less specialist intellectual disability mental health services than those without ASD (as measured by the Service Consumption Score; SCS). However, this was not because they had less need or increased use of other health services. They lived in residential placements with a significantly higher ratio of staff to service users than those without ASD. Although the difference was not significant, participants with ASD received more hours of support staff per week than those without ASD. It is not clear whether this extra layer of support leads to lower mental health service use. There is some evidence that different models of residential care impact on challenging behaviour which in turn influences quality of life (Gerber et al., 2011).

A study of the costs of ASD to the economy estimated that the amount spent on community health and social care[1] for each adult with intellectual disability and ASD per year was just £581 (Knapp et al., 2009). This contrasts greatly with the amount spent on residential (£36 233) and hospital services (£4 588). The National Audit Office (2009a) suggested that improving access to effective specialist services for people with ASD would significantly reduce overall costs to the economy, particularly with regards to local authority spending[2] whilst improving outcomes for individuals. However, the report acknowledged that this would only be possible if identification rates increase.

It was not clear why participants with ASD used fewer mental health services than those without ASD. It was not because their mental health or behaviour was better and therefore

[1] Not including respite care, day services, education, employment support or benefits
[2] On supported accommodation/residential care homes, day services, employment service & education

they required less intervention. The main factors driving this difference were that some participants with ASD did not use any mental health services for 12 months and they were less likely to be on the Care Programme Approach (CPA). The number of participants without ASD who were on the CPA was similar to that found in other mental health services (Stewart et al., 2009).

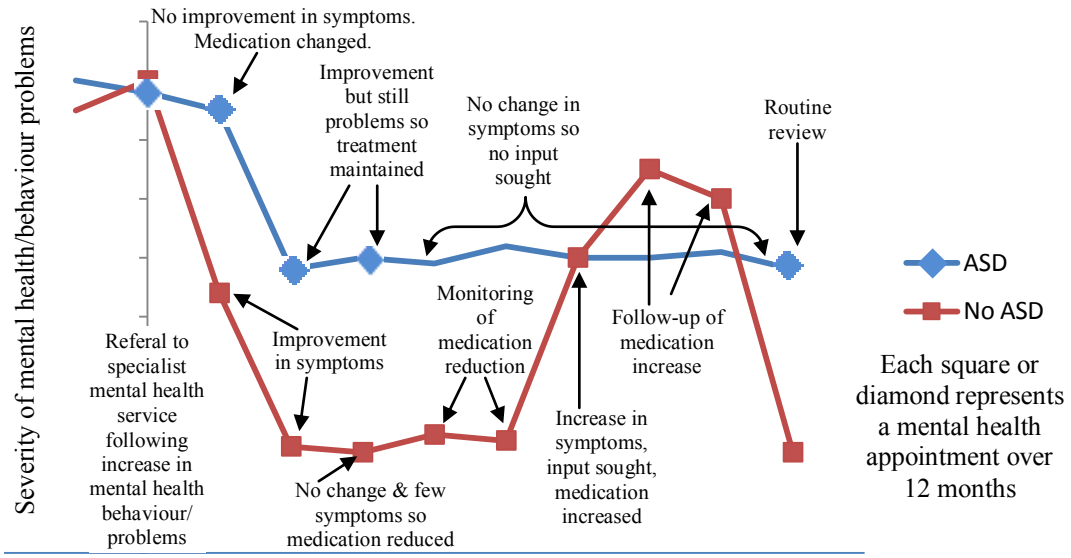
The Department of Health (2006a) has previously stated that individuals with intellectual disability, ASD and *"...significant mental health needs will almost certainly require enhanced CPA."* (pp. 21). Significant mental health needs are not explicitly defined but even among those with ASD and a psychiatric diagnosis only four participants (17%) were on the CPA.

Bhaumik et al. (2008a) argued that service users with intellectual disability should be categorised according their level of need and developed a three level criteria. People with high needs would be on the Care Programme Approach (CPA) and receiving multi-professional care at least once a fortnight; those with medium needs would have fortnightly to three monthly input from one or two professionals; and those with low needs would receive input once every three months in the form of an outpatient review with one professional. The importance of identifying the characteristics of those with a high level of need was highlighted (Bhaumik et al., 2008a).

Despite have higher levels of need, it appeared that those with ASD tended to receive a less enhanced service and were more likely to not receive any mental health service over 12 months. There was no evidence that participants with ASD were more likely to drop out of specialist mental health services. Service users are discharged if they do not attend three consecutive appointments. So it is likely that participants who had no mental health service use but remained on the caseload had not been offered an appointment for over a year.

An explanation for the disparity in service use between those with and without ASD is that the poorer mental health and behaviour of those with ASD is chronic but fairly stable over time. This means they do not have as many episodes where they require an increased level of service input. By contrast, those without ASD have periods when their mental health and behaviour fluctuates. This leads them to access services to seek adjustments in their medication or treatment. This could also explain why service users tend to use specialist mental health services for so long. Their mental health either fluctuates necessitating longer term follow-up and monitoring (service users without ASD/with a psychiatric disorder) or their mental health and behaviour is always poor and they require continuous treatment (service users with ASD/without a psychiatric disorder). This suggestion is illustrated in Figure 12.2.

Figure 12.2: Suggested pattern of service consumption for those with & without ASD



An unpublished audit of specialist mental health service users with intellectual disability found that the majority of those with ASD had little change in mental health symptoms over time (McCarthy & Kannabiran, 2010). Furthermore there were few changes to their

medication following their second mental health appointment. Unfortunately, the same information for those without ASD was not collected. Further longitudinal studies are needed to examine whether there is any evidence for this. These should compare matched groups of those with and without ASD.

A small proportion of participants (33%) were using a very large amount (80%) of the mental health services consumed by participants over 12 months. Briefly, this group were more likely to have mild intellectual disability, a psychiatric disorder, live with family or independently than those with lower levels of mental health service use. More research is needed on who these individuals are and why they consume such a high proportion of services.

A previous study on consumption of specialist mental health services by those with intellectual disability also found that a small number of service users were consuming a large number of services (Spiller et al., 2007). The only significant predictor of SCS was diagnosis of psychotic disorder. However, this study found no significant relationship between any specific psychiatric disorder and service consumption. Participants with psychotic disorder comprised 23% of the sample and used 24% of the services consumed.

There is much debate about whether challenging behaviour should be viewed as a mental health issue and whether individuals with challenging behaviour should be receiving mental health services (Baker & Daynes, 2010). Lower level challenging behaviour is likely to be seen as a psychosocial problem and the point at which it becomes a psychiatric problem is unclear and undefined. Slater & Baillie's (2008) audit of referrals to an intellectual disability psychology service indicated that challenging behaviour accounted for more than 42% of referrals. It would appear from the clinical study that probably most of these individuals would have ASD.

It was clear from the data that when adults with intellectual disability suffer from mental health problems they require specialist treatment over a long period of time. Those who used specialist mental health services for a shorter amount of time did not appear to have any different characteristics from those who were longer term service users. Length of service use was not significantly associated with participants' mental health or social functioning.

Mental health and social functioning

Most participants had fairly low scores on the HoNOS-LD and DBC. Mean scores were lower than those found at the baseline or endpoint of previous intervention studies (Dowling et al., 2006; Hall et al., 2006; Pridding & Tomasoni, 2006). Furthermore, 51% of participants in the main study had a good to excellent rating of social functioning and most of those with ASD had a fair to excellent rating. However, there was evidence that particular subgroups did not have as positive outcomes as others. These included individuals with ASD, those with severe intellectual disability and those with no diagnosis of psychiatric disorder.

The study found that severity of intellectual disability was a significant predictor of total number of needs, mental health service consumption score, psychotropic medication use and social functioning. Previous studies on adults with ASD found strong relationships between low IQ/intellectual disability and poor social functioning (Beadle-Brown et al., 2009; Billstedt et al., 2005; Eaves & Ho, 2007; Howlin et al., 2004; Lockyer & Rutter, 1969; Lotter, 1974; Rutter et al., 1967).

There was consistent evidence that participants with ASD had higher needs, lower mental health service use, poorer mental health and social functioning than those without ASD. However, for mental health service use, needs and social functioning; ASD was not a significant predictor once severity of intellectual disability was taken into account. Few studies have considered whether IQ or cognitive functioning are more important predictors of

social functioning than ASD itself. This is largely because they have not included matched comparison groups of people without ASD.

It was not possible to compare the results for participants with ASD with previous studies on social functioning because of the different methods used to measure and define this outcome. The finding that severity of intellectual disability and having challenging behaviour were important predictors of social functioning replicates earlier results (Beadle-Brown et al., 2009; Felce et al., 2011; Totsika et al., 2010).

Only one previous study could be found that was specifically designed to compare the social functioning of adults who had intellectual disability with and without ASD (Esbensen et al., 2010). Those with ASD had significantly poorer social functioning than those with Down syndrome (DS). Most of the participants with ASD had moderate to low social functioning whereas most of those with DS had moderate social functioning. There was a much higher proportion of participants with severe intellectual disability among those with ASD, however in regression analyses severity of intellectual disability was not a significant predictor of social functioning (Esbensen et al., 2010).

Levels of independent living and employment were much lower among participants in the study than other studies of adults with ASD (Cederlund et al., 2008; Howlin et al., 2000; Farley et al., 2009; Mawhood et al., 2000; Renty & Roeyers, 2006). It is not clear whether this reflects participants' lower levels of functioning compared with those in previous studies. It could relate to the difficulties that people with additional mental health or behavioural problems have finding and maintaining employment. The overall rate of employment among participants (16%) was similar to previous estimates by the Foundation for People with Learning Disability (2007). However, 27% of those without ASD had a job suggesting that this group were achieving better levels of employment than expected. Although all but one of

these participants were in part-time, supported or voluntary employment rather than full-time jobs. Around a fifth of participants were not engaging in any scheduled activities, a result similar to the findings of a survey by the National Autistic Society (Barnard et al., 2001) and a Spanish study on quality of life (Saldana et al., 2009).

The original hypotheses for the thesis were based on the literature and followed the premise that: adults with intellectual disability and ASD have higher levels of need; this would lead to higher levels of mental health service use; but despite this, and because many of their needs remained unmet, they would have poorer mental health, and social functioning compared to those without ASD. This model was not confirmed by the results of the study.

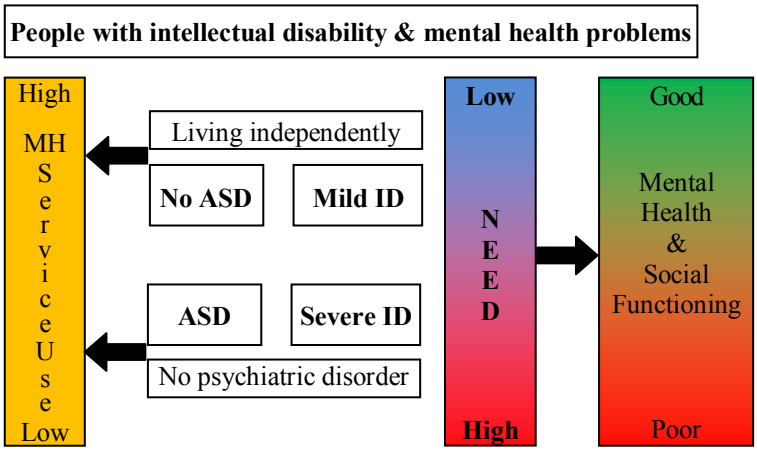
Total level of need and met need were higher among those with ASD and were also associated with mental health, behaviour and social functioning. However, those with higher levels of need had significantly poorer mental health, behaviour and social functioning regardless of whether those needs are being met. This could indicate that poorer mental health and social functioning are characteristic of adults with intellectual disability and ASD and cannot be improved even with increased attempts to meet their needs.

Alternatively instead of trying to meet a need, perhaps services and interventions should aim for the person to have no need in the first place. For example, enabling someone to independently buy and prepare their own meals rather than having them provided. Esbensen et al. (2010) found that those with intellectual disability and ASD had poorer life skills than those Down Syndrome and suggested that improving skills and activities should be a key goal of services and may lead to improved outcomes. It is not clear how many of the items in the CANDID could feasibly be eliminated so that an individual went from having a met or unmet need to no need.

Further research is needed to determine the exact nature of the needs that most predict mental health and social functioning. This could be achieved by identifying subdomains within the CANDID through factor analysis or exploring which specific items appear to be related to social functioning. It will be important to establish whether the needs that predict social functioning are the same for individuals with and without ASD or at different levels of intellectual disability severity. Given the low internal consistency of the CANDID it may be that an alternative measure of need should be developed.

Based on the results of the study, a revised model of the relationships between variables is shown in Figure 12.3. The higher an individual's needs the less able they are to access effective services and the poorer their mental health and social functioning.

Figure 12.3: Model of relationships between needs, service use and outcome



The study provides limited evidence for this model as it did not establish a direct link between service use and needs or mental health and social functioning but it may help to explain why some service users have poorer mental health and social functioning. It could be a useful theoretical starting point for future research.

An explanation for this hypothesis could be that current mental health services for adults with intellectual disability are not well equipped to deal with those who have ASD and/or very

high levels of need. As a result they are either not providing an effective service for these individuals or when they are it does not matter how much input an individual has their mental health and social functioning does not improve.

In any case, within this service model for adults with intellectual disability who have mental health problems there was a small but significant number of individuals whose mental health and social functioning was poorer. The following strategies could be considered to improve this situation:

Develop distinct care pathways and protocols within specialist mental health services for adults with intellectual disabilities based on individuals' levels of need. Needs should be assessed at an individual level but it should be recognised that at a group level those with the highest needs are likely to have moderate/severe intellectual disability and/or ASD. This approach is supported by advocates of personalised health and social care including the Department of Health (2006b; 2007b; 2010b).

Further differentiation could be achieved by improving access to mainstream mental health services for those who have mild intellectual disability, psychiatric disorder and low levels of need. If these people were not consuming as many specialist mental health services there would be more resources available and the service could be better tailored to serve those with higher levels of need including people with moderate/severe intellectual disability and ASD. This would bring services more into line with national policy that states individuals with intellectual disability should be accessing mainstream mental health services where possible (Department of Health, 2001b).

Alternative, the provision of specialist mental health services for adults with intellectual disability should be focussed on those with psychiatric disorder. Individuals with higher

levels of need and behaviour problems would access a specialist behavioural service that may better serve their needs.

It is likely that these options would require additional resources or a reconfiguration of existing resources. However as described earlier, there is evidence that improving access to specialist services and enhancing current assessment and intervention for ASD would lead to savings in the long term (National Audit Office, 2009a).

An alternative explanation for the results is that the tools used by the study (HoNOS-LD, DBC and social functioning scale) measured ASD and cognitive functioning more than they assessed mental health and social functioning. Although the HoNOS-LD and DBC both contain items that are related to features of ASD they also contain many that are unrelated. Furthermore, significant differences between those with and without ASD remained when these ASD-specific items were removed. Although the difference between the mean scores became smaller it was clear that participants with ASD had higher scores over a wide range of mental health and behavioural problems than those without ASD.

The study found that participants with ASD had poorer scores across all three HoNOS-LD subdomains – neuro-cognitive functioning, mental health/behaviour and health/social functioning. However, in the clinical study the items that participants with ASD scored higher than those without ASD on were all ASD-type features. Similarly, those with ASD scored higher than those without ASD on the DBC self-absorbed, communication disturbance and social relating subscales. All these DBC subscales could be said to relate to characteristics of ASD whereas there was no difference between the groups for the subscales that relate more to mental health: anxiety/anti-social and depressive.

The degree of overlap between features of intellectual disability or ASD and psychopathology is such that for many symptoms it is very difficult to determine whether someone is experiencing a problem because of their developmental disability or because they have a mental health problem. Establishing the onset of an individual's problems can help to overcome this; any that have been present over a long period of time or since early childhood are more likely to be related to ASD or intellectual disability rather than psychopathology (Deb et al., 2001a). Finding out more about the nature of an individual's symptoms can also help to determine their origin. A commonly cited example is obsessions and compulsions; common features of ASD but more likely to be an indicator of OCD if there is evidence that the individual finds them distressing and attempts to resist them (WHO, 1992).

These overlaps cause difficulties when carrying out diagnostic assessments and should be taken into consideration when making a diagnosis and treatment plan. However, in many respects when it is general 'mental health' that is being measured (as represented by the DBC); the source of an individual's problems is not as salient. The important issue is that they are experiencing a problem that is having a negative impact on their life or the lives of those around them. The aim of the thesis was to determine whether adults with intellectual disability and ASD had poorer mental health and social functioning compared to those without ASD rather than explore the cause of their problems.

As described in Chapter 11, there were 14 participants in the main study with globally poor mental health and social functioning. Despite receiving specialist mental health services for an average of 5½ years this group had the highest HoNOS-LD and DBC scores and the lowest social functioning scale scores. It is not possible to ascertain what the scores of these individuals were when they were referred to specialist mental health services but it does not appear that the treatment they have received has resulted in a positive outcome. Almost 30%

were not receiving any psychotropic medication at the time of their informant interview (none of these individuals had been diagnosed with a psychiatric disorder); the rest were all on antipsychotics. Five participants had no contact with specialist mental health services for 12 months and only three were on CPA. However, nine were receiving behavioural or psychological input (including two of those with no specialist mental health service contact).

Further research would be needed to explore why these participants' mental health and social functioning was not as good as the rest of the sample. Specifically, it would be useful to comprehensively reassess their mental health to find out whether there was any evidence that they:

- were receiving treatment for a psychiatric disorder but in fact did not have one and required more behavioural intervention, or
- had an undiagnosed psychiatric disorder for which they were not receiving effective treatment (e.g. medication).

As discussed earlier, there was some evidence that ADHD, in particular, appeared to be under-diagnosed in this group of service users who exhibited high levels of inattention and hyperactivity.

Previous research has found that the misdiagnosis of psychiatric disorder is common among mental health service users with intellectual disability and/or ASD (Bradley et al., 2011a). Further evidence that this is a significant determinant of outcome would lend weight to the argument that services should be taking steps to ensure that the way in which service users are assessed results in consistent and reliable diagnoses.

Participants with ASD traits and behaviours

The study identified some noteworthy features of participants who had no clinical diagnosis of ASD but were excluded because they exceeded the ADOS threshold or appeared to meet ICD-10 criteria for ASD. These could be useful indicators that an individual should be further assessed for ASD. They may also be part of the reason that ASD has gone unrecognised. For example, a high proportion (25%) of those with no clinical diagnosis of ASD had epilepsy and most of these participants (13 out of 19) were excluded.

This could be because:

- Diagnostic overshadowing of behaviours relating to epilepsy and ASD symptoms means that ASD symptoms are overlooked in those with epilepsy.
- Treatment with anticonvulsant medication reduces ASD-type behaviours and therefore individuals go undiagnosed.
- Individuals with epilepsy have reduced social communication skills that limit their ability to take part in the ADOS assessment.

Other characteristics that this may apply to include people with an identifiable cause of their intellectual disability and those who are non-verbal (see Chapter 11).

It may be the case that individuals with undiagnosed or unrecognised ASD have different patterns of ASD symptoms compared to those who receive a clinical diagnosis. There may be a threshold of certain ASD behaviours above which a diagnosis is triggered; while other behaviours cause problems for an individual but do not lead to formal, clinical diagnosis of ASD. Participants with ASD traits/behaviours had poorer mental health and social functioning than those without ASD therefore it is important that they are effectively identified and have their needs assessed.

Reliability and validity

The methods chosen for the study performed satisfactorily and the results did not appear to have been unduly influenced by measurement bias. There were few problems administering the chosen measures to adults with intellectual disability and their informants. The validity of the social functioning scale was enhanced by developing it in consultation with an expert service user who had intellectual disability.

Comparing the main study sample to the wider clinic population

Potential participants approached to take part in the main study were not randomly sampled. As a result there was an increased possibility of selection bias. There was an additional element to consider since many of those approached were unable to consent for themselves and a consultee was appointed to decide on their behalf. Families and support staff often acted as influential barriers or facilitators of access to potential participants regardless of whether they had capacity.

To check for any selection bias, the results of the main study were compared to results from the supplementary clinic study determine how representative participants were of the wider specialist mental health service user population. A comparison of participants with ASD included in the clinic study and the 53 recruited into the main study revealed no significant differences between the samples. Participants in the main study without a clinical diagnosis of ASD were significantly different to the clinic study participants without ASD. It is likely that this was partly due to initial attempts to recruit matching groups of participants with and without ASD. Those with no ASD in the main study were younger, more likely to be male and have severe intellectual disability than those with no ASD in the clinical study.

The pattern of differences between participants with and without ASD in each study was broadly similar. The only noteworthy disparity was that the pattern of psychiatric disorder

was slightly different. There were fewer participants with ASD and depression and more participants without ASD who had depression in the main study leading to a significant difference between the ASD groups.

The internal consistency of the HoNOS-LD was lower for the main study than it was for the clinical study but this could be because of the much larger dataset used in the latter. The size of the difference in total HoNOS-LD scores between the ASD groups in the main study (mean difference of nine) was greater than that found between those with and without ASD in the clinic study (mean difference of five). This was because the mean score of those with ASD in the main study was higher than those with ASD in the clinical study (19.8 vs. 18.2). Plus the mean score of those without ASD was lower than those without ASD in the clinical study (11 vs. 13). The clinic study included participants subsequently excluded from the main study. It is possible that these individuals were contributing to an inflated mean HoNOS-LD score. The mean HoNOS-LD score of the 76 participants in the main study with no clinical diagnosis of ASD was 12.7, closer to the mean score in the clinic study, which appears to support this argument.

In conclusion, participants with ASD in the main study were not significantly different from those in the clinic study. Therefore it appears reasonable to generalise the results for those with a confirmed diagnosis of ASD included in the main study to those with a clinical diagnosis of ASD in the wider sample of specialist mental health service users with intellectual disability.

Measures

The study aimed to assess participants using the most suitable measures available. However, it should be noted that the measures selected have some limitations. For example, social functioning was measured using a scale especially constructed for the study that relied on data

collected using other tools. As such, this measure has not been validated nor have its psychometric properties been evaluated beyond internal consistency. The method of developing the scale was based on previous studies on the social functioning of adults with ASD (Howlin et al., 2000; Howlin et al., 2004; Lotter, 1974; Marriage et al., 2009; Mawhood et al., 2000). However, it is acknowledged that this did not follow standard methods of scale development. Further testing of this scale among wider groups of adults with intellectual disability is needed. Further development of the scale may benefit from clinician and carer input.

The study did not use a standardised measure of problem behaviour. Instead, a subscale was derived from the DBC. Again, this was developed following a review of existing scales and has not been validated. Therefore, the results of analyses that included this measure should be interpreted with caution.

The study used the HoNOS-LD as a measure of health and social functioning. This is used as an outcome measure within clinical services but has not been extensively used in research. Many items relate to functioning and as such there may be a ceiling effect whereby participants with more severe intellectual disability will tend to score highly because of deficits in their memory, attention, and ability to communicate. Therefore, it may be more useful to look at differences between those with and without ASD on the three HoNOS-LD subscales (neuro-cognitive functioning, mental health/behaviour and health/social functioning) rather than the total score.

Limitations and strengths

When evaluating the limitations and strengths of the studies it is important to consider that they aimed to provide a snapshot of the mental health and social functioning of specialist mental health service users with intellectual disability and ASD. They were not designed to

measure the prevalence of mental health problems in adults with intellectual disability or evaluate the effectiveness of specialist mental health services for adults with intellectual disability. Other key issues that should be taken into account when assessing the studies include the well known difficulties when recruiting people with intellectual disability, ASD and mental health problems into research and lack of evidence-based tools available for this service user group.

Limitations of the study

Aside from issues of relying on clinical diagnoses which were discussed earlier, the main limitations of the studies for the thesis were:

- Use of a single, specialist mental health service in a geographical area not representative of the UK
- Inability to recruit matched samples
- Reliance on informants for collection of data on participants
- Lack of test re-test or inter-rater reliability data for informant interviews
- Use of assessors who were not always blind to participants' ASD status

Use of a single service

The participants were all sourced from a single community mental health service for adults with intellectual disability. As such, the participants are not representative of the national intellectual disability population within the UK. It is therefore not possible to generalise the findings beyond their relevance to the provision of mental health services to adults with intellectual disability.

As discussed in Chapter 5 this type of specialist service – provided separately from local community intellectual disability services – is unusual within the UK (Chaplin et al., 2009). It

is also located in a part of London that is quite different from the rest of the country with regards population density and socio-economic demographics (Stewart et al., 2009). As such these service users may not be representative of the wider population of adults with intellectual disability who have mental health problems. There are several groups of individuals that this study did not include:

- Adults with intellectual disability and mental health/behaviour problems who are placed out of area or admitted to an inpatient unit.
- Adults with intellectual disability and mental health/behaviour problems who are not referred to/accepted to the specialist mental health service but receive psychological/behavioural input from a community intellectual disability team.
- Adults with intellectual disability and mental health/behaviour problems who are not referred to or accepted in to either of these services.

That is, those with the most and least severe problems may not have been included. The pattern of differences between those with and without ASD may be different among people in these groups. More research is needed on broader populations.

However, the service user group included provided an excellent opportunity to access a clearly defined sample of individuals (the service has stringent eligibility criteria) and explore the service model that has developed in this area (the service also has well-defined operational criteria). The results of the thesis provide a useful evidence-base on which to design further research on wider samples.

Matching

When designing the study, it was thought that matching participants with and without ASD would be vital and that disentangling the effects of intellectual disability severity and ASD

would be very difficult. It emerged that this was the case for the HoNOS-LD and social functioning scale, but not the DBC. Although severity of intellectual disability was associated with differences in DBC score it did not exert as high an influence as anticipated. In the regression analyses, it was not a significant predictor of DBC score. This is most likely because the DBC contains mainly mental health and behavioural items compared with the more health and social functioning focus of the HoNOS-LD.

Every attempt was made to recruit samples with and without ASD that were well-matched on severity of intellectual disability. Ultimately, this was not possible because of the high proportion of participants with moderate and severe intellectual disability who failed to meet the study criteria for 'no ASD'. These participants were also more likely to be male and have no additional psychiatric disorder therefore it was not possible to match on these variables because there were no service users among the remaining sample who had the necessary characteristics. Of 15 recruited participants with severe intellectual disability and no clinical diagnosis of ASD only one was included in the study. This level of undiagnosed ASD was not anticipated in such a specialist service. More research is needed to explore why so many individuals exceeded the ADOS thresholds for ASD.

The high level of undiagnosed ASD and inability to match groups with and without ASD throws into question the reliability of previous studies; especially those that relied on clinical diagnoses of ASD. It seems likely that many of the participants in the no ASD comparison groups of these studies in fact have ASD; particularly those with severe intellectual disability.

Informant-based data

A concern for studies that include individuals with a range of intellectual disability severities is that it becomes necessary to rely on informant-based data. This can introduce measurement

bias (Rojahn et al., 1994). It could be argued that there is a qualitative difference in the information provided by a family carer who has looked after someone 24 hours a day for their whole life compared with a paid carer who works with the person for a limited amount of time each week and may not have known them long. There is some evidence that type of informant can affect ratings of mental health (Kanne et al., 2009a). However the use of informants is standard practice in intellectual disability and ASD research (Hutton et al., 2008).

Furthermore, studies have found little difference between results from informant and self-rating scales (Gordon et al., 2007). The accuracy of the service use data provided by informants is unclear. In some cases it was possible to look back through well-kept diaries and obtain information on participants' appointments in the previous 12 months. At other times the memory of the informant was relied on. However, the Client Service Receipt Inventory was designed for use with an informant and has been found to have good agreement with case records (Patel et al., 2005).

Lack of inter-rater reliability data and assessor blinding

All the informant interviews were carried out by a single researcher. As such there were no inter-rater reliability data to assess the measures used. It was also not possible to re-administer the measures to obtain test-retest data. However, the advantage of using one researcher is that bias introduced by multiple raters is eliminated. An alternative measure of reliability – internal consistency – was calculated for the CANDID, DBC, HoNOS-LD and SCQ.

Another disadvantage of using one researcher was that this was the same person who recruited participants. As such the informant interviews were not carried out by a researcher who was blind to whether the participant did or did not have ASD. This was also the case for

many of the ADOS assessments. A consultant psychiatrist carried out the review using ICD-10 criteria of those who did not take part in an ADOS assessment. It was not revealed whether or not the participants had a clinical diagnosis of ASD but this may have been obvious from their mental health record.

None of these limitations hindered the ability of the study to address the key aims of the thesis. Any difficulties interpreting the results were related more to the heterogeneity of the participants and complexity of the relationships between the variables that were explored.

Strengths of the study

The main strengths of the studies for the thesis were:

- Good sample sizes
- Inclusion of adults with a range of intellectual disability severity
- Inclusion of well-defined comparison groups of those without ASD
- Standardised assessment of ASD using the ADOS and expert review
- Standardised measures used to collect data on a wide range of variables
- A social functioning scale specifically for adults with intellectual disability developed in consultation with an expert who has intellectual disability

Studies on the characteristics and differences in the prevalence of mental health problems between those with and without ASD have ranged in sample size from 24 to 752. The main study's sample size of 98 participants provided sufficient power to detect significant differences between those with and without ASD. The clinical study included 788 participants in the main analyses. This compares well with previous studies on the prevalence of ASD among adults with intellectual disability (see Table 3.2).

Studies that have measured the mental health of adults with ASD compared to those without ASD rarely used a standardised diagnostic assessment of ASD. Furthermore, few previous studies on the social functioning of adults with ASD included any comparison group (see Table 4.2). Therefore, the inclusion of participants without ASD and confirmation of presence/absence of ASD using the ADOS were major advances on earlier work.

The main strength of the thesis was the use of a 'gold standard' ASD assessment, in addition to clinical diagnosis. The decision to include this safeguard was supported by the high number of participants who were excluded from the no ASD group because they exceeded the threshold for ASD. It is not clear whether these individuals had undiagnosed ASD. Their characteristics were more similar to those with ASD and their mental health and social functioning was different from those without ASD; justifying their exclusion from the main analyses.

It should be noted that the ADOS alone is not sufficient to make a diagnosis of ASD in an adult. It is for this reason that those with no clinical diagnosis who exceeded the ADOS threshold were excluded from the study rather than transferred into the ASD group. It was not possible to carry out standardised assessment based on participants' developmental history; using the ADI-R for example. However, all participants in the ASD group had a clinical diagnosis made by a specialist intellectual disability psychiatrist using ICD-10 criteria. This assessment would have included an investigation into the individual's developmental history where possible.

The breadth of the data collected made it possible to build up a detailed description of relationships between participant characteristics, service use, mental health and social functioning. It also allowed the analyses to take a wide range of variables into account when comparing participants with and without ASD. The use of three measures presented the

opportunity to explore participants' mental health, behaviour and social functioning from different angles:

- A short-term look at health and social functioning over a broad range of domains for the last four weeks plus exploration of subscales including behavioural items (HoNOS-LD),
- a longer-term measure of mental health and behavioural symptoms over six months plus exploration of subscales (DBC),
- and a composite measure of current independence, communication, social interaction, community involvement and structured activity (social functioning scale).

The results were fairly consistent: participants with ASD had poorer scores on all of these measures.

The inclusion of the specially devised social functioning scale was particularly important because the choice of domains was made from the perspective of someone with intellectual disability. None of the previous studies on the social functioning of adults with ASD included any input from individuals with ASD or intellectual disability in the development of their measures. The involvement of a service user expert influenced what was included in each domain, the way each level of the items were scored and how the overall rating of social functioning was calculated. The design of the social functioning scale meant that participants with and without ASD could be meaningfully compared. If measures from previous studies had been used most of the participants would have had a poor or very poor social functioning. The data would have been skewed and it would have been more difficult to assess whether there were differences between those with and without ASD.

Previous studies have often found contradictory results when comparing adults who have intellectual disability with and without ASD. When they are examined more closely it emerges that there are questions about whether those in each group really did or did not have ASD, how they measured prevalence of psychiatric disorder, how they assessed mental health and social functioning, and whether the results can be generalised to the full spectrum of adults with intellectual disability. The strengths described above, acknowledgement of limitations and explicitly stated, standardised methods used in the studies for the thesis increase confidence in their findings.

How the study adds to the evidence-base

The literature review for the thesis revealed that there has been a lack of high-quality research on the impact of ASD on the mental health and social functioning of adults with intellectual disability. The study was designed to build on previous work and add to the current evidence base on whether there are differences between specialist mental health service users who have intellectual disability with and without ASD.

Assessment and diagnosis

Current evidence

There are a wide range of assessment tools for ASD but few are suitable for adults with intellectual disability. There is a lack of evidence on whether mental health assessment tools for adults with intellectual disability have different psychometric properties when used with those who also have ASD.

What the study adds

The ADOS was found to be a useful tool for adults with intellectual disability. It enabled the study to successfully establish two groups of participants who, it could be reliably said, did

and did not have ASD. However, the high number of participants who exceeded the threshold for ASD indicates that its sensitivity and specificity needs further investigation.

The low sensitivity of the SCQ means that it probably should not be used to screen for ASD as this would results in a high number of false negatives. However, an indicator that an individual does not require a full diagnostic assessment would be if they meet clinical criteria for ASD and have an SCQ score higher than 15. A five-item subscale within the HoNOS-LD could flag up those with unrecognised ASD traits/behaviours. More research is needed to develop this scale.

The measures used to assess participants needs, mental health and social functioning did not appear to have significantly different psychometric properties when used with people who have ASD. The DBC appeared to be a reliable measure of mental health for individuals who have intellectual disability with and without ASD.

Prevalence and comorbidity

Current evidence

The estimated rate of ASD among adults with intellectual disability ranges from 8 to 40%. Studies on mental health service users with intellectual disability have found rates of around 20%. High quality studies on the prevalence of psychiatric disorder have found limited evidence for similar or slightly lower rates of psychotic disorder, and higher rates of depression, bipolar and anxiety disorders among those with ASD.

What the study adds

Among specialist mental health service users with intellectual disability, the rate of clinically diagnosed ASD was around 34%. However, a further 22% may have undiagnosed ASD. The clinical study provided further evidence that adults with intellectual disability and ASD are not more vulnerable to psychotic disorders. There was some indication that they are more

likely to have anxiety and ADHD than those without ASD although the rate of these disorders was not particularly high.

Needs, service use and medication

Current evidence

It is known that adults with intellectual disability and ASD require high levels of support but there is evidence that they do not get the help they need for mental health problems. The care pathway for this group usually leads to specialist intellectual disability services.

What the study adds

Even when the mental health problems of adults with intellectual disability and ASD are recognised and they are referred to specialist services, they do not have the same level of access to these services as those without ASD, despite having higher needs.

Mental health and social functioning

Current evidence

There is limited evidence that adults with intellectual disability and ASD have higher levels of mental health and behavioural problems and poorer social functioning than those without ASD. However, severity of intellectual disability and challenging behaviours may be more important predictors of these factors than ASD.

What the study adds

Previous findings on non-clinic populations appear to hold true for adults with intellectual disability who receive specialist mental health services. For this group, number of needs is a more important predictor of mental health and social functioning than either of ASD, intellectual disability severity or presence/absence of a psychiatric diagnosis. The results also provided some evidence that the relationship between intellectual functioning and social

functioning among those with ASD persists as IQ drops below 50 (moderate to severe intellectual disability).

Recommendations for policy, practice and future research

The focus of the thesis was whether specialist mental health service users with intellectual disability and ASD have different characteristics, needs, service use, mental health, behaviour and social functioning to those without ASD. Therefore, the results primarily have implications for specialist mental health services for adults with intellectual disability in the UK. It is vital that these services better understand their users. This includes recognising the importance of characteristics that group individuals together and impact on their needs and outcomes. Evidence from the thesis indicates that these characteristics include the presence of ASD, moderate to severe intellectual disability and presence/absence of a psychiatric disorder.

Once recognised and better understood these characteristics (either at a group or individual level) should inform:

- The delineation of assessment and care pathways.
- The identification of people that services should be prioritising for improved access to assessment, services and monitoring.
- Choice of evidence-based intervention.

The areas highlighted by the thesis that could lead to better outcomes for specialist mental health service users with intellectual disability include:

1. Efforts to identify groups and individuals who are not effectively accessing services and increase equity of access, particularly among those with high needs.

2. Better assessment and monitoring of needs using standardised methods plus proactive intervention to meet or eliminate specific needs.
3. Improved assessment and monitoring of outcomes, ensuring that action is taken when outcomes do not improve. This includes proactively identifying factors that may be limiting an individual's opportunity for a better outcome.
4. Improved awareness and understanding of ASD. Among support staff and carers but also health and social care staff including providers of specialist mental health services for adults with intellectual disability.
5. Improved diagnostic assessment. Both for ASD in order to better understand an individual's presentation and for psychiatric disorders to better inform treatment and care decisions. This should include comprehensive and consistent reassessment of new service users (whether they have existing diagnoses or not), service users whose symptoms have not responded to treatment, and those who have persistent and chronic symptoms or whose outcomes are poor.
6. Better established assessment and care pathways for ASD, service users with severe intellectual disability, those with and without a psychiatric disorder and those with high levels of need.
7. Less fragmented assessment of need and implementation of care packages across the range of health and social services that adults with intellectual disability use.

Future research

Areas in which more research is needed have been highlighted throughout the thesis. These include further collection and analysis of data from specialist mental health services with intellectual disability to:

- Develop and test the five-item HoNOS-LD subscale identified by the clinical study as a first-line screening measure for ASD among adults with intellectual disability who have mental health problems.
- Determine the level of undiagnosed ASD among specialist mental health service users with intellectual disability. Specifically by determining whether those with ASD traits/behaviours meet the criteria for a diagnosis.

Further studies from wider samples are needed to find out:

- Building on the recommendations made by the NICE guideline for ASD in adults (2012). What are the key symptoms or behaviours that should prompt an assessment for ASD in adults with intellectual disability?
- Whether using current algorithms of the ADOS for adults with intellectual disability and mental health problems results in too many false positives?
- What steps can be taken to better equip services and clinicians to carry out more consistent diagnostic assessments of mental health problems in adults with intellectual disability and/or ASD?
- What factors determine whether adults with intellectual disability who have mental health problems get referred to specialist services?
- Among adults with intellectual disability, which individuals are using high levels of mental health services and why?
- Which specific needs are the strongest predictors of social functioning among those using specialist mental health services for adults with intellectual disability?

In addition to these specific questions, a range of other points on health services research on adults with intellectual disability and/or ASD were raised. Few studies of adults with intellectual disability report the number of participants with ASD or investigate whether presence of ASD has any impact on their findings. The situation is similar for research on adults with ASD which does not always take intellectual disability into account unless it is specifically on those with low-functioning ASD.

The current study found that:

- The rate of ASD among adults with intellectual disability who use specialist mental health services could be as high as 56%.
- Those with ASD form a distinct group among adults with intellectual disability.
- Adults with ASD and intellectual disability have different patterns of mental health, problem behaviour and social functioning to those without ASD.

This has considerable implications for the reliability and validity of studies which fail to take into account the impact of ASD on participants' outcome.

A number of issues undermine epidemiological research on intellectual disability, ASD and comorbid mental health problems. Many studies that purported to measure prevalence of psychopathology were actually designed to test the psychometric properties of an assessment tool. Furthermore, scale and screening tools often were used in place of proper diagnostic assessment. Many instruments include subscales with cut-off points for particular types of symptoms but these do not always match diagnostic criteria or are not adequately validated against standardised diagnoses.

Research on adults with intellectual and ASD often blurs the boundaries between problem behaviours and psychiatric disorder; grouping them together or using behavioural measures to ascertain prevalence of psychopathology. This makes it hard to estimate the prevalence of comorbid psychiatric disorder among people with intellectual disability and ASD. This crossover is one of the key areas of difficulty when evaluating the evidence for or against a relationship between challenging behaviour and mental health problems. As discussed in Chapter 2, these challenges are difficult to avoid since the assessment and diagnosis of intellectual disability, ASD and comorbid mental health problems is largely based on behavioural symptomatology but studies need to be clearer in their methods and analysis.

In summary, mental health services users with intellectual disability and/or ASD are heterogeneous populations with complex needs. Research needs to more clearly define, assess and differentiate between severities of intellectual disability, high- and low-functioning ASD, mental health problems and challenging behaviour. Studies on the prevalence of intellectual disability, ASD or psychiatric disorder need to ensure that data on multiple diagnoses are accurately captured.

Conclusion

A significant proportion of specialist mental health service users with intellectual disability have ASD. Although it appears that individuals with ASD are overrepresented in these services there does not appear to be evidence that they are more vulnerable to psychiatric disorder than those without ASD. Many individuals with intellectual disability and ASD receiving mental health services do not have a diagnosis of psychiatric disorder but are receiving treatment for challenging behaviour.

Currently, most adults who have intellectual disability with and without ASD share a common care pathway. Once they reach specialist services there are few assessment or care protocols

in place to meet the specific needs of those with ASD. There appears to be an assumption that specialist mental health services for adults with intellectual disability have sufficient expertise and resources to effectively recognise ASD and provide effective evidence-based intervention.

The thesis found evidence that ASD goes unrecognised or undiagnosed in a considerable number of specialist mental health service users with intellectual disability. Data from participants with and without a confirmed diagnosis of ASD indicated that those with high levels of need, moderate and severe intellectual disability and no diagnosed psychiatric disorder were receiving lower levels of service and had poorer mental health, behaviour and social functioning. In some cases, these clinical factors were more significant predictors of mental health, behaviour and social functioning than ASD itself but most of the service users who fitted these profiles had ASD.

There will always be some service users whose outcomes are less positive than others. However, within this sample these individuals formed a consistently distinct group and were consuming the least amount of services. The results suggest that the current model does not provide fully accessible and effective services for individuals with high needs such as those with ASD, severe intellectual disability and challenging behaviour that requires specialist assessment and intervention.

Proposals to improve this include:

- Specialist assessment and intervention services for adults with ASD (including those who are low-functioning). This may not help those without ASD who have high needs who would continue to receive services according to the current model (e.g. those with severe intellectual disability).

- Greater access to mainstream services for those with low levels of need.
- Separate specialist services for adults with intellectual disability who have a psychiatric disorder and those who have challenging behaviour.
- One 'neurodevelopmental' service for all those with intellectual disability and/or ASD. Such a service could incorporate different pathways for those with and without additional psychiatric disorder.

The recent NICE guidelines have highlighted the current lack of evidence on the best ways of recognising and managing ASD among adults (NICE, 2012). The recommendations made particular reference to the need for more research on what structure and organisation of specialist teams are associated with improved outcomes for adults with ASD. The thesis has provided some evidence that there is a need for intellectual disability services to rethink their approach to assessing and managing ASD. However, this should be evaluated within the context of the study's limitations. These include the way in which mental health, problem behaviour and social functioning were measured; the highly selected nature of the sample and the number of participants included.

Nonetheless the thesis provides a platform on which to build further research as described above. It may also serve as a baseline comparison for futures studies on whether recent initiatives such as the Autism Strategy and recommendations by NICE on setting up local autism strategy multi-agency groups do in fact lead to an increase in ASD recognition among specialist mental health service users with intellectual disability.

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Appendices

Appendix I: Publications

The following papers have been published subsequent to peer-review, are in press or are in preparation for submission to peer-reviewed journals.

Underwood et al., 2011a

Published as:

Underwood, L., McCarthy, J. & Tsakanikos, E. (2011). Assessment of Co-morbid Psychopathology. in J.L.L. Matson and P. Sturmey. *International Handbook of Autism and Pervasive Developmental Disorders*. New York, Springer 17, 287-293.

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Underwood et al., 2012

Published as:

Underwood L, McCarthy J, Tsakanikos E, Howlin P, Bouras, N & Craig, T. (2012). Health and social functioning of adults with intellectual disability and autism. Journal of Policy and Practice in Intellectual Disabilities 9 (2) 147-150

[Full text unavailable in electronic version of the thesis due to copyright restrictions]

Underwood et al, 2010

Published as:

Underwood L, McCarthy, J & Tsakanikos, E (2010). Mental health of adults with autism spectrum disorders and intellectual disability. Current Opinion in Psychiatry 23 (5) 421-426.

[Full text unavailable in electronic version of the thesis due to copyright restrictions]

Tsakanikos et al., in preparation

To be submitted as:

Tsakanikos, E., Underwood, L., McCarthy, J. & Arshad, S. Psychometric properties of the Health of the Nation Outcome Scale for people with Learning Disabilities (HoNOS-LD). *Research in Developmental Disabilities.*

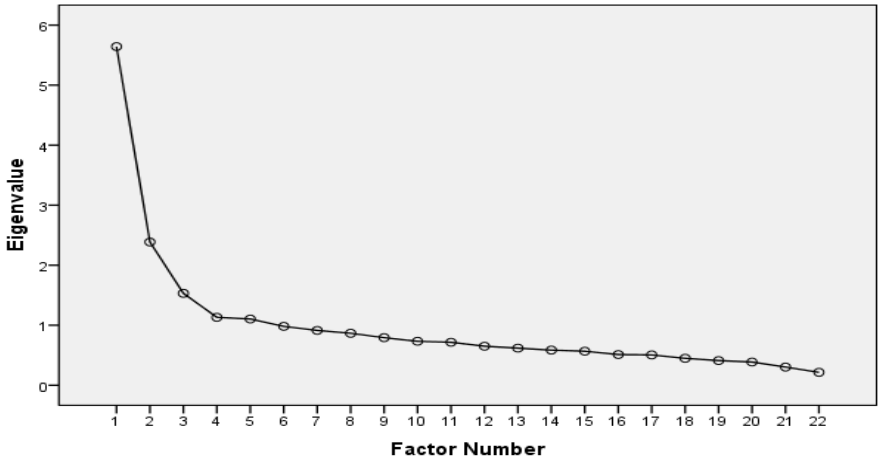
Aim: To identify domains within the HoNOS-LD using statistical factor analysis.

Method: Data were sourced from the anonymised case records of past and present mental health services users in South East London. A search was carried out to identify all service users who had received a HoNOS-LD assessment since electronic records were implemented in 2006. Individual item and total scores were obtained for participants' most recent HoNOS-LD assessment.

Results: The search identified 2032 mental health service users with HoNOS-LD assessments carried out between April 2005 and December 2010. The mean age of participants was 43 (SD=14; range 18-91) and 45% were female. HoNOS-LD scores ranged from zero to 75 with a mean of 14.1 (SD=10.4).

A principal axis factoring analysis with Promax rotation was carried out. There were five factors with Eigenvalues greater than one. However, an examination of the Scree plot indicated a three factor solution (Figure 0.1).

Figure 0.1: Scree plot for the factor analysis of 2032 HoNOS-LD assessments



The factor analysis was rerun with three factors extracted. The pattern matrix showed that the first factor contained five items relating to memory, attention, expressive and receptive communication, and seizures (see Table 1). The second factor contained the behavioural items of the HoNOS-LD plus those relating to symptoms of mental health problems.

The remaining items related to participants' physical health, access to the community, activities/occupation, self-care and relationships.

These items appeared to fit well together in a way that was clinically meaningful. The three factors were labelled 'Neuro-cognitive functioning', 'Mental & behavioural problems' and 'Health & social functioning'.

Table 1: Three factor pattern matrix for the HoNOS-LD

HoNOS-LD Items	Factor		
	1	2	3
Receptive com	.918	.029	-.156
Expressive com	.872	.016	-.071
Memory	.616	-.011	.124
Attention	.553	.136	.181
Seizures	.204	.015	.058
Destructive beh	.041	.722	-.085
Personal habits	.084	.631	-.036
Stereotypy	.246	.617	-.101
Beh to others	.037	.540	.017
Other beh	.022	.488	.023
Mood changes	-.219	.469	.330
Anxiety	-.043	.437	.166
Beh to self	.070	.420	.062
Hallucinations	-.120	.278	.167
Occupation	.024	.022	.600
Daily living at home	.353	-.083	.597
Activities outside home	.361	-.135	.590
Self-care	.191	.074	.475
Eating probs	-.100	.130	.386
Relationships	-.098	.290	.374
Sleeping probs	-.128	.228	.374
Physical probs	.130	-.083	.300
Extraction Method: Principal Axis Factoring. Rotation Method: Promax with Kaiser Normalization.			
a. Rotation converged in 9 iterations.			

The reliability of these groupings was explored. The Internal consistency (Cronbach's alpha) of the subscales is shown in Table 2.

Table 2: Internal consistency of the HoNOS-LD subscales

HoNOS-LD Subscale	α
Neuro-cognitive functioning	0.804
Mental health/behavioural problems	0.779
Health & social functioning	0.759

Conclusion: Three HoNOS-LD subscales were identified by factor analysis. The items within these scales fitted well together and had good internal consistency.

Appendix II: Clinic study data collection

CRIS confirmation of approval

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CRIS searches

Search fields:
((Referrals_Episodes.Team_episode.Site_Code="02342") AND
(Referrals_Episodes.Team_episode.Referral_Admin_Status_ID="Accepted")) OR
((Referrals_Episodes.Team_episode.Site_Code="02300") AND
(Referrals_Episodes.Team_episode.Referral_Admin_Status_ID="Accepted")) OR
((Referrals_Episodes.Team_episode.Site_Code="02257") AND
(Referrals_Episodes.Team_episode.Referral_Admin_Status_ID="Accepted"))

Output fields:
brcid,dob,ethnicitycleaned,Core_Info.Address.Address_Type_ID,Core_Info.EPR_Form.First_Year_Of_Care_Date,Core_Info.EPR_Form.Gender_ID,Core_Info.EPR_Form.Marital_Status_ID,Core_Info.EPR_Form.Lives_With_ID,Core_Info.EPR_Form.Employment_ID,Core_Info.EPR_Form.DAT_Of_Residence_ID,Core_Info.EPR_Form.Housing_Status,Core_Info.Team_member.Location_Name,Core_Info.Team_member.Location_Team_Ward_ID,Core_Info.Team_member.Staff_Name,Assmnts.Diagnosis.Comments,Assmnts.Diagnosis.Primary_Diag,Assmnts.Diagnosis.Secondary_Diag_1,Assmnts.Diagnosis.Secondary_Diag_2,Assmnts.Diagnosis.Secondary_Diag_3,Assmnts.Diagnosis.Secondary_Diag_4,Assmnts.Diagnosis.Secondary_Diag_5,Assmnts.Diagnosis.Secondary_Diag_6,Medications.Medication.Medicine_ID,Medications.Medication.Medication_Dose,Medications.Medication.Medication_Frequency,Medications.Medication.Medication_Start_Date,Outcomes.CANDID.Assessment_Date,Outcomes.CANDID.Number_Of_Met_Needs_User_Total,Outcomes.CANDID.Number_Of_Met_Needs_Staff_Total,Outcomes.CANDID.Number_Of_Unmet_Needs_User_Total,Outcomes.CANDID.Number_Of_Unmet_Needs_Staff_Total,Outcomes.CANDID.Number_Of_Needs_User_Total,Outcomes.CANDID.Number_Of_Needs_Staff_Total,Outcomes.HoNOS_LD.Degree_Of_Learning_Disability_ID,Outcomes.HoNOS_LD.Nature_Of_Accommodation_ID,Outcomes.HoNOS_LD.Total,Outcomes.HoNOS_LD.Adjusted_Total

Search fields:
((Referrals_Episodes.Team_episode.Site_Code="02300") AND
(Referrals_Episodes.Team_episode.Referral_Admin_Status_ID="Accepted")) AND
((Correspondence.Attachment.Attachment_Text="2009") OR
(Correspondence.Attachment.Attachment_Text="2008")) OR
((Referrals_Episodes.Team_episode.Site_Code="02342") AND
(Referrals_Episodes.Team_episode.Referral_Admin_Status_ID="Accepted")) AND
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Output fields:
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Appendix III: Clinic study results

Table III.1: Diagnoses included in each category of psychiatric disorder in Table 10.3

Type of disorder	Diagnostic label as entered into mental health record
ADHD	ADHD, hyperkinetic conduct disorder, hyperkinetic disorder
Anxiety disorder	Agoraphobia, Anxiety disorder, Generalised Anxiety Disorder, Mixed anxiety disorder, Obsessive Compulsive Disorder, Other anxiety disorder, Other neurotic disorders, Post-Traumatic Stress Disorder, Specific phobia
Bipolar disorder	Bipolar affective disorder, Bipolar disorder, Hypomania, Manic episode with psychotic symptoms
Dementia	Alzheimer's dementia, Cognitive decline, Vascular Dementia
Depression	Depressive episode, Depressive disorder, Depressive disorder with psychotic symptoms, Depressive Illness, Mood disorder, Psychotic depression, Recurrent depression/depressive disorder/depressive episode
Personality disorder	Borderline personality disorder, Dependent personality disorder, Emotionally unstable personality disorder, Emotionally unstable Personality disorder (Borderline type), Emotionally unstable personality disorder (impulsive type), Paranoid Personality Disorder, Personality disorder, unspecified
Psychotic disorder	Acute & transient psychotic disorder, Catatonic schizophrenia , Delusional disorder, Organic delusional disorder, Organic Psychotic disorder, Other non-organic psychotic disorder, Paranoid schizophrenia, Persistent Delusional Disorder, Psychosis unspecified, Psychotic & affective disorder, Psychotic episode, Residual Schizophrenia , Schizoaffective disorder, Schizophrenia, Simple schizophrenia, Unspecified non organic psychosis, Unspecified psychotic illness
Other	Acute Stress Reaction, Adjustment disorder, Affective and anxiety disorder, Eating disorder, Gender identity disorder, unspecified, mixed affective disorder, Mixed anxiety and depression, Oppositional Defiant Disorder

Table III.2: Total HoNOS-LD scores for those with & without ASD by other variables

	ASD (N=200)	No ASD (N=361)
Males	17.6 (9.3)	13.2 (9.5)
Females	20.4 (10.1)	12.8 (8.7)
Psychiatric disorder	*16.3 (9.7)*	*12.9 (9.1)*
Behaviour impairment (N=552)	*20.6 (8.7)*	*13.5 (9.3)*
Mild	12.6 (8.6)	11 (8)
Moderate	19 (9)	15.9 (9.5)
Severe intellectual disability	23.5 (7.7)	23.8 (8.8)
Afro-Caribbean	18.5 (9.2)	11.5 (9.1)
Asian	22.8 (9.6)	11.1 (8.1)
White	17.3 (9.8)	13.7 (9.4)
Other	21.4 (7.3)	12.5 (6.6)
Living with family	16.9 (9.1)	13.7 (9.4)
Independently	13.8 (10.4)	10.1 (8)
Residential placement	19.7 (9.7)	13.7 (9.3)
Other type of residence (N=555)	11.4 (4)	16.4 (7.2)
Psychotic disorder	16.2 (10.7)	11.3 (7.7)
Anxiety	16.5 (7)	15.8 (9.5)
Depression	17.3 (9.8)	13.3 (9.3)
Bipolar	15.8 (8.5)	10.6 (8.3)
Personality Disorder	N/A	9 (5.8)
Dementia	31 (N=1)	25 (11)
Other	15.2 (10.6)	13.4 (7.9)

Table III.3: Correlations between age and HoNOS-LD subscales

		CogincEpi	MHBeh	HSFunc
Age	Pearson Correlation	.090*	-.125**	.049
	Sig. (2-tailed)	.034	.003	.246

Table III.4: ANOVA results for HoNOS-LD subscales

		N	Mean	SD	Df	F	p
CogincEpi	Female	228	3.64	3.642	1	3.927	.05
	Male	333	4.28	3.837	559		
					560		
MHBeh	Female	228	4.48	4.125	1	.020	.888
	Male	333	4.53	3.972	559		
					560		
HSFunc	Female	228	6.23	4.309	1	.231	.631
	Male	333	6.42	4.592	559		
CogincEpi	Asian	30	4.37	3.222	3	.128	.943
	Black	142	4.08	3.730	557		
	White	353	3.96	3.864	560		
	Unclear or other	36	4.06	3.513			
MHBeh	Asian	30	4.43	4.232	3	.165	.920
	Black	142	4.32	4.042	557		
	White	353	4.57	4.082	560		
	Unclear or other	36	4.72	3.403			
HSFunc	Asian	30	6.97	4.916	3	.218	.884
	Black	142	6.31	4.368	557		
	White	353	6.32	4.552	560		
	Unclear or other	36	6.17	3.866			
CogincEpi	Family	152	3.78	3.523	3	16.974	.000
	Placement	315	4.80	3.952	551		
	Other	12	2.83	2.588	554		
	Independent	76	1.58	2.311			
MHBeh	Family	152	5.00	3.932	3	2.918	.034
	Placement	315	4.51	4.204	551		
	Other	12	5.33	4.250	554		
	Independent	76	3.38	3.302			
HSFunc	Family	152	6.48	4.308	3	1.185	.315
	Placement	315	6.54	4.539	551		
	Other	12	6.17	3.070	554		
	Independent	76	5.49	4.675			
CogincEpi	Psych Disorder	404	3.49	3.564	F (1, 551)=31.6, p<0.001		
	No Psych Disorder	148	5.47	3.944			
MHBeh	Psych Disorder	404	4.15	3.923	F (1, 551)=11.2, p<0.001		
	No Psych Disorder	148	5.44	4.183			
HSFunc	Psych Disorder	404	6.17	4.524	F (1, 551)=, p=0.113		
	No Psych Disorder	148	6.85	4.362			
CogincEpi	Mild ID	319	2.07	2.322	2	200.919	.000
	Moderate ID	156	5.49	3.680	558		
	Severe ID	86	8.57	3.089	560		
MHBeh	Mild ID	319	3.81	3.663	2	18.159	.000
	Moderate ID	156	4.79	4.184	558		
	Severe ID	86	6.63	4.290	560		
HSFunc	Mild ID	319	5.47	4.273	2	17.748	.000
	Moderate ID	156	6.98	4.499	558		
	Severe ID	86	8.41	4.348	560		

Appendix IV: Ethical approval

Confirmation of ethical approval from St Thomas' REC

Original application

[Documents removed from pdf version to reduce file size]

Amendment one

[Documents removed from pdf version to reduce file size]

Amendment two

[Documents removed from pdf version to reduce file size]

Confirmation of approval from the Institute of Psychiatry R&D Office

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Appendix V: Main study materials

Capacity Assessment

CAPACITY CHECKLIST

Go through each question. If the service user is unable to give an adequate answer, **do not** tick the "Yes" box, explain the answer & move on to the next question.

1. **Does the person understand the information?** **Yes:** ☐
   Do you think you understand what the research is about?
   Do you understand what will happen if you agree to take part?
   Do you understand what will happen if you don't agree to take part?

2. **Can the person retain the information?** **Yes:** ☐
   Can you tell me what you understand about the research?
   Can you tell me what you think will happen if you agree to take part?
   Can you tell me what you think will happen if you don't agree to take part?

3. **Can the person use or weigh the information?** **Yes:** ☐
   What do you think about taking part?
   What do you think will be good about taking part?
   Do you think there might be anything bad about taking part?

4. **Can the person communicate the decision (by any means)?** **Yes:** ☐
   Do you understand that you can say yes or no to taking part?
   Have you decided whether you will say yes or no to taking part?
   Would you like to take part in the research? (tick "Yes" above regardless of whether they do or do not want to take part, so long as they can give an answer)

If you have been unable to tick "Yes" for all four conditions, go through the information sheet with the service user again. Then go through the questions they were unable to answer first time around.

Has the service user demonstrated capacity to consent to take part in the study?
I.e. Have you ticked "Yes" for all four conditions above?

Yes ☐ **No** ☐

If "Yes", detail why you think the person **has** capacity to consent

_____
_____
_____
_____

If "No", detail why you think the person **does not have** capacity to consent

_____
_____
_____
_____

Please sign to confirm that you have carried out the above procedure

_____ **Date:**_____

Service user consent form

South London and Maudsley NHS
NHS Foundation Trust

Estia Centre
Munro - Guy's Hospital
66 Snowfields
London SE1 3SS
020 3228 9738

www.estiacentre.org

KING'S College LONDON
Founded 1829
University of London

Research project on Mental Health of People with Learning Disability

Service User Consent Form

Principal investigator: Dr Jane McCarthy, Estia Centre

Name of service user:

This is the consent form. Please read the form carefully.

✓	The purpose of the research has been explained to me.
✓	I have been given an information sheet about the research.
✓	I have been given the chance to ask questions about the research.
✓	I understand that the researcher will need to get some information from my records

✓	I understand the researcher will need to get some information from someone who knows me well.
✓	I understand that the researcher will need to speak to my carer.
✓	I understand that I might get invited to an assessment at the outpatient clinic
✓	I understand that I can take a break if I need to.
✓	I understand that if I say yes and then change my mind, that is ok.
✓	I understand that what I say will be kept strictly private.
✓	I understand that if the researcher is worried about me, he/she will talk to my carers or doctor.
✓	I understand that people from the Department of Health may want to look at my records to check the researcher's work.

If you agree with what has been said, please sign this form.

☐ I **agree** to take part in this research

☐ I do **not** agree to take part in this research

If you agree to take part please tick **one** of these boxes:

☐ I **agree** to come to a meeting with my carer

☐ I do not want to go to the meeting with the researchers but I **agree** that my carer can go.

Print name_____

Sign name_____ Date: ___/___/___

Person taking consent

I have discussed the research with the participant, and *(tick either box (a) or box (b))*

(a) I have answered questions that were asked about the research

(b) The participant had no questions to ask about the research.

Researcher's signature……..

Researcher's name in block letters……..…….

This study is funded by the Baily Thomas Trust, sponsored by the Institute of Psychiatry & has received ethical approval from St Thomas' Hospital Research Ethics Committee.

Consultee assent form

South London and Maudsley NHS
NHS Foundation Trust

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KING'S College LONDON
Founded 1829
University of London

Research study on
Mental Health Problems of People with Learning Disability

Consultee Assent Form

Principal investigator: Dr Jane McCarthy, Estia Centre

Name of service user: [Participant's name]

Please read this form carefully

✓ The purpose of the research has been explained to me.

✓ I have been given an information sheet about the research.

✓ I have been given the chance to ask questions about the research.

✓ I understand that I am agreeing that **[Participant's name]** can participate in this research study.

I understand that I am free to withdraw my agreement at any time,

✓ and do not have to give any reason for this.

✓ I understand that **[Participant's name]** can take a break if he needs to.

✓ I understand that all information obtained in the study will be kept strictly confidential, although any information which causes the researcher concern will be passed on to **[Participant's name]**'s care team.

✓ I have considered what the wishes and feeling's of **[Participant's name]** would be if she[he] had capacity to decide whether to take part.

If you agree with all of the above, please sign your name and write the date below.

Sign your name_____ Date_____

Print your name_____

This study is funded by the Baily Thomas Trust, sponsored by the Institute of Psychiatry and has received ethical approval from St Thomas' Hospital Research Ethics Committee

Participant information sheet

South London and Maudsley NHS
NHS Foundation Trust

Estia Centre
Munro - Guy's Hospital
66 Snowfields
London SE1 3SS
020 3228 9738

KING'S College LONDON
Founded 1829
University of London

Research project on Mental Health of People with Learning Disability

Service User Information Sheet

Principal investigator: Dr Jane McCarthy, Estia Centre

Who are we?

We work for the Estia Centre

We help people with learning disability who have mental health problems.

We are doing a research project.

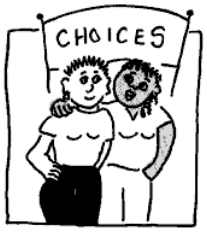
The project is about the mental health of people with learning disability.

What do we want to know?

If you have mental health problems, you might feel sad or hear voices.

We want to know:

1. Do mental health problems get better, get worse or stay the same?



2. Do you get the help you want?

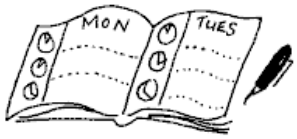
Once we know this, we can help you and other people better.

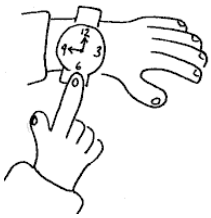
PART ONE
Everyone
☺ ☻ ☻ ☺ ☺ ☺ ☺ ☺
☺ ☺ ☻ ☺ ☺ ☻ ☺

PART TWO
Everyone
☺ ☻ ☻ ☺ ☺ ☺ ☺ ☺
☺ ☺ ☻ ☺ ☺ ☻ ☺

PART THREE
About half the people
☺ ☻ ☻ ☺
☺ ☺ ☻

Everyone
☺ ☻ ☻ ☺ ☺ ☺ ☺ ☺
☺ ☺ ☻ ☺ ☺ ☻ ☺





What do we want to do?

There are three parts to the study.

We will ask everyone to do part one and part two.

We will only ask some people to do part three. We will tell you if we would like you to do part three.

PART ONE

We would like to meet with someone who knows you well.

We want to talk about –

- you and your problems
- what help you get, your medication and how people look after you
- if you need help with anything else

You can decide:

- if we meet you and your carer
- if we meet just your carer

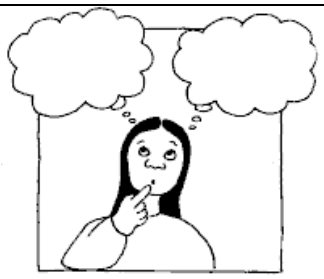
We will only talk to your carer if **you** agree.

How long will it take?

The meeting will take about 2 hours.

PART TWO

We would like to look at your medical records.

Everyone ☺ ☻ ☻ ☺ ☺ ☺ ☺ ☺ ☺ ☺ ☻ ☺ ☺ ☻ ☺ About half the people ☺ ☻ ☻ ☺ ☺ ☺ ☻ 	**PART THREE** We will ask some people to come to the outpatient clinic for a meeting. A researcher will ask you to do some activities (for example: describe a picture). The researcher will write down what you do or say. The activities will take about 45 minutes. You can take a break at any time. If you get upset in the meeting please tell the researcher. If you get upset, we can stop. If you are upset, we will talk to your carers. If you get upset after the meeting please tell your keyworker or someone at home.
	You can choose: • if you want to help us • if you don't want to help us You can take 14 days to think about it. You do not have to take part if you do not want to. If you say yes and then change your mind, that is ok. You do not have to give us a reason why you have changed your mind. **Your care will be the same if you say yes or no.**

	If you say yes -
Part one	We will talk to your carer.
Part two	We will look at your file.
Part three	We might invite you to do some activities.
	**Do you get paid?**
	Sorry, we cannot pay you to help us
	We can pay for your travel
	Will anyone find out what you and your carer have said?
	Everything you say will be private. Your information will be kept safely. Your name will not be on any letters or reports. If we are worried about you, we will talk to your carers or your doctor.
	People from the Department of Health may want to look at our information to check our work.
	What if you are not able to understand the study (lack capacity)?
	If this happens before the study, we will ask someone who knows you well to decide whether you should take part.
	If this happens after the study we will still keep a record of your information and use it in our research.
	What happens after our study?
	We will talk to lots of people like you.

We will then write a report.

We will send you a copy of the report, if you would like one.

What if I have a concern or complaint?

If you have any questions, concerns or complaints please telephone

Doctor Jane McCarthy on 0203 228 9738.

You can write to her at: The Estia Centre, 66 Snowsfields, London, SE1 3SS.

If you are still unhappy you can make a complaint through the NHS Complaints Procedure. Ask your GP or the team that is responsible for your care and treatment.

What happens now?

There is a form with this information. Please send this back to us.

Please fill out the form if you think you would like to help. Tick the **Yes box.**

This study is funded by the Baily Thomas Trust, sponsored by the Institute of Psychiatry and has received ethical approval from St Thomas' Hospital Research Ethics Committee

Service user profile

Age last birthday ☐☐

Ethnicity

White British	1	Indian	9
White Irish	2	Pakistani	10
Other White	3	Bangladeshi	11
Mixed White and Black Caribbean	4	Other Asian	12
Mixed White and Black African	5	Black Caribbean	13
Mixed White and Asian	6	Black African	14
Other Mixed	7	Other Black	15
Chinese	8	Other Ethnic Group (please specify)_____	16

Nationality

British	1	Other (please specify) _____	2

First language _____

Relationship status

Married/civil partnership	1	Divorced/dissolved civil partnership	3
Single	2	Widowed	4
Other (please specify) _____	5	Not known	6

Level of educational

No education	1	Community college	5
Primary education or less	2	Tertiary/further education	6
Secondary education	3	Other (please specify)	7
Special education	4	_____	

Age when left school/education ☐☐

Informant profile

Mental Health Outcomes in Adults with LD

Data Collection Pack – Informant Interview

1. Relationship of informant to service user: _____

_____

2. Approx. length of time informant has known service user:

☐☐ years, ☐☐ months Or tick here if informant has known service user all their life (e.g. for a family member) ☐

3. Number of contacts per week with service user: ☐☐

Or tick here if service user lives with the informant so there's contact every day ☐

Circle the appropriate box for each item.

4. Age group of informant

16 - 24	1	45 – 54	4
25 – 34	2	55-64	5
35 – 44	3	Over 65	6

5. Gender of informant

Male	1	Female	2

6. Ethnicity of informant

White British	1	Indian	9
White Irish	2	Pakistani	10
Other White	3	Bangladeshi	11
Mixed White & Black Caribbean	4	Other Asian	12
Mixed White & Black African	5	Black Caribbean	13
Mixed White & Asian	6	Black African	14
Other Mixed	7	Other Black	15
Chinese	8	Other Ethnic Group	16

Case note review schedule

Mental Health Outcomes in Adults with LD

Data Collection Pack – Case note review

Please take care to note the period of time that should be rated.

Service user ID:

Period of rating: from ☐☐/☐☐/2 0☐☐ = interview minus 1 year

To ☐☐/☐☐/2 0☐☐ = date of interview

Date of rating: ☐☐/☐☐/2 0☐☐

Name of Rater: _____

Is this person on the current MHiLD caseload? Yes 2 **No** 1

Are there any existing measures on ePJS? Yes 2 **No** 1

If "Yes", which measures have been taken, when and what was the result?

HoNOS-LD 1 Date: ☐☐/☐☐/☐☐☐☐ Score: ☐☐

HoNOS 2 Date: ☐☐/☐☐/☐☐☐☐ Score: ☐☐

CANDID 3 Date: ☐☐/☐☐/☐☐☐☐ Met needs: ☐☐

Unmet needs: ☐☐

Total needs: ☐☐

Other 4

Name:_____ Date : ☐☐/☐☐/☐☐☐☐ Score: ☐☐

Name:_____ Date : ☐☐/☐☐/☐☐☐☐ Score: ☐☐

Name:_____ Date : ☐☐/☐☐/☐☐☐☐ Score: ☐☐

SERVICE USER PROFILE

N.B. For severity of learning disability, psychiatric diagnosis and current medication, priority should be given to the last follow-up letter to the service user's GP as this is likely to be the most accurate and up to date information.

Date of birth: ☐☐/☐☐/19☐☐

Gender: Male [1] Female [2]

Current MHiLD team:

Lambeth [1] Lewisham [2]

Southwark [3] Other (please specify) [4]

_____

What is the service user's degree of learning disability?

If different severities are mentioned in different sources of information, make a note of these in the margin then circle the answer that seems most consistent in the service user's notes. Try to give a definitive severity (e.g. mild) unless it is always stated to be something else (e.g. mild/moderate).

Borderline [1] Severe [4]

Mild [2] Profound [5]

Moderate [3] Other (e.g. mild to moderate) [6]

Please specify:_____

Unclear [7] _____

Does the service user currently have a psychiatric diagnosis?

Yes [2] **No** [1]

Write the diagnosis/es as worded on ePJS, make a note if there are any differences in the diagnosis given in different sources of information._____

_____

_____

_____

_____

_____

_____

Does the service user currently have a diagnosis of PDD/ASD?

Yes [2] **No** [1]

If "Yes", how is this recorded? Write the diagnosis/es as worded on ePJS, make a note if there are any differences in the diagnosis given in different sources of information.

[1] Definite diagnosis Where on ePJS?_____
Classification/details?_____

[2] Suspected Where on ePJS?_____
Details?_____

[3] Other Where on ePJS?_____
Details?_____

[4] Cannot find any mention of ASD, autism, Asperger's or PDD

Does the service user have epilepsy? **Yes** [2] **No** [1]

Does the service user have any physical disabilities, illnesses or problems (including sensory impairment)? **Yes** [2] **No/unclear** [1]

If yes, please specify:

_____

_____

Current CPA status

No CPA [1]

Standard CPA [2] Enhanced CPA [3]

Current legal status

Informal [1] Other Section MHA [3]

Guardianship [2] Other, please specify [4]

_____

Occupation of care co-ordinator

Psychiatrist [1] Psychologist [3]

Nurse [2] Other, please specify [4]

_____

INITIAL INVOLVEMENT WITH MHiLD

Date of referral to MHiLD*:* ☐☐/☐☐/☐☐☐☐

Tick here if the date is unclear from current records: ☐

Reason for referral to MHiLD:_____

_____

Tick here if the reason is unclear from the records: ☐

Source of referral to MHiLD:

GP	1	Hospital or other doctor	4
Residential Support staff	2	Voluntary services	5
Social Services staff	3	Other (please specify)	6
		_____	
Unclear	7		

Borough of MHiLD team at referral:

Lambeth	1	Lewisham	2
Southwark	3	Other (please specify)	4
		_____	
Unclear	5		

Legal status referral:

Informal	1	Other Section MHA	3
Guardianship	2	Other, please specify	4
		_____	
Unclear	5		

Type of residence at referral to MHiLD:

Family home	1	Independently	4
Hospital	2	Some other place (please specify)	5
Supported home	3	_____	
Unclear	6		

On assessment, was the service user diagnosed with a psychiatric disorder? Yes [2] **No** [1] **Unclear** [3]

Write the diagnosis/es as worded on ePJS:_____
_____

On <u>initial</u> assessment, was the service user diagnosed with a PDD?

Yes [2] **No** [1] **Unclear** [3]

Write the diagnosis/es as worded on ePJS:_____
_____

Following referral what clinical management action decision was taken?

Further involvement from MHiLD?	**Yes**	[2]	**No**	[1]
Admission to Weston Unit?	**Yes**	[2]	**No**	[1]
Recommended pharmacotherapy?	**Yes**	[2]	**No**	[1]
Referral to Psychology/Challenging Needs?	**Yes**	[2]	**No**	[1]
Referral to Social Services?	**Yes**	[2]	**No**	[1]
Referral to OT?	**Yes**	[2]	**No**	[1]
Referral to Speech and Language Therapy?	**Yes**	[2]	**No**	[1]
Referral to Physiotherapy?	**Yes**	[2]	**No**	[1]
Admission to Adult Psychiatric Unit?	**Yes**	[2]	**No**	[1]
Referral to General Hospital Physician/Surgeon?	**Yes**	[2]	**No**	[1]
Discharged to GP's care?	**Yes**	[2]	**No**	[1]
Other? Please specify:	**Yes**	[2]	**No**	[1]

_____

Tick here if this is unclear from current records: ☐

SUMMARY OF THE RATING PERIOD

Please write in all the things that happened to the service user during the rating period. Include life events, appointments and all contacts with health or social care services, changes in care/treatment/medication. DO NOT USE THE SERVICE USER'S NAME.

List the items in chronological order with dates (use an additional sheet if necessary):

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

SERVICES AND TREATMENTS RECEIVED DURING THE RATING PERIOD

Assessment and review	During rating period		Date of most recent	Date previous to that
When was the service user last seen by a MHiLD clinician?	Yes	No	☐☐/☐☐/☐☐ Details of contact:	☐☐/☐☐/☐☐ Details of contact:
Care or care plan review	Yes	No	☐☐/☐☐/☐☐	☐☐/☐☐/☐☐
Risk assessment	Yes	No	☐☐/☐☐/☐☐	☐☐/☐☐/☐☐

List of current medication	Dose	Started on	Started by (name)

Medication	During the rating period		If YES number in each group
Antipsychotics	Yes	No	
Mood stabilisers	Yes	No	
Antidepressants	Yes	No	
Benzodiazepines	Yes	No	
Antiepileptic medication	Yes	No	
Other medication (e.g. Beta blockers) – please specify:	Yes	No	

Interventions	During the rating period		If YES - No. of sessions
Behaviour therapy/intervention	Yes	No	
Cognitive or cognitive behavioural therapy (CBT)	Yes	No	
Individual therapy	Yes	No	
Group therapy	Yes	No	
Parental/ intervention	Yes	No	
Staff training	Yes	No	
Change of environment (e.g. of placement) – please specify:	Yes	No	
Family intervention	Yes	No	
Consultation with other agencies – please specify:	Yes	No	
Other, please specify:	Yes	No	

Community-based services **Mental Health in Learning Disability Service (MHiLD)**	In last 12 months? Yes	No	No. of visits	No. of home visits
Community psychiatrist MHiLD - **outpatient appointments**	Yes	No		
Community psychiatrist MHiLD - excluding outpatient visits	Yes	No		
Community psychiatric nurse	Yes	No		
Community Learning Disability Team	Yes	No		
Community psychiatrist. **Outpatient appointments**	Yes	No		
Community psychiatrist - excluding outpatient visits	Yes	No		
Learning disability nurse	Yes	No		
Psychologist	Yes	No		
Behaviour support worker or behavioural therapist	Yes	No		
Physiotherapist	Yes	No		
Occupational therapist	Yes	No		
Social worker/Approved social worker	Yes	No		
Speech and language therapist	Yes	No		
Art/drama/music therapist	Yes	No		

Community-based services	In last 12 months?		No. of visits	No. of home visits
Other CLDT member. Please specify:	Yes	No		
General Adult Mental Health Services	Yes	No		
Community psychiatrist - other than from MHiLD service – **outpatient appointments**	Yes	No		
Community psychiatrist - other than from MHiLD service - excluding outpatient visits	Yes	No		
Community psychiatric nurse	Yes	No		
Other community mental health team member. Please specify:	Yes	No		
Other community services	**Yes**	**No**		
General Practitioner	Yes	No		
Other community nurse (e.g. district nurse, health visitor) – please specify:	Yes	No		
Dentist	Yes	No		
Optician	Yes	No		
Chiropodist	Yes	No		
Alternative therapist (e.g. reflexologist)	Yes	No		
Advocate/counsellor	Yes	No		
Home help/home care worker	Yes	No		
Employment services/job centre	Yes	No		
Other community worker – please specify:	Yes	No		
Any other services or workers – please specify	Yes	No		
	Yes	No		

Hospital-based services	In last 12 months?		If YES - No. of inpatient days or appointments
Learning disability psychiatric ward	Yes	No	
Psychiatric intensive care ward	Yes	No	
Acute psychiatric ward	Yes	No	
Psychiatric rehabilitation ward	Yes	No	
General medical ward	Yes	No	
Long stay ward	Yes	No	
Other specialty inpatient-ward. Please specify:	Yes	No	
Day hospital	Yes	No	
Accident and emergency department	Yes	No	

REFERRAL PATHWAYS

Note here any referrals made by MHiLD **or** any other agency in the last 12 months and the results of the referral.

Date of referral	Referral by:	Referral to:	Result
□□/□□/□□			
□□/□□/□□			
□□/□□/□□			
□□/□□/□□			
□□/□□/□□			

Is there anything else you feel it's important to mention that has not already been covered in the case note review? Include here anything major that has happened to the service user since the informant interview took place (include details and dates).

_____
_____
_____
_____
_____

Table V.1: Measures reviewed during the development of the social functioning scale

Howlin et al., 2000; Mawhood et al., 2000 Four composite measures: Language, Friendship, Independence & Autistic-type stereotyped behaviours. Each rated 0 (normal/near-normal), 1 (moderate/fair) or 2 (poor/very poor). Composite score (sum of above) comprising 3 levels: 0-1 = near normal functioning. 2-4 = moderate difficulties. 5-8 = considerable levels of difficulty Language: Good (uses sentences with mature grammar, understands 2/3-step instructions, talks with others so that conversation flows, able to build on other person's dialogue) = 0. Fair (scores positively on 2 of the above) = 1. Poor (scores on only 1) = 2. Very poor (scores on none) = 2. Friendships: Good (normal relationship) = 0, Fair (some limited friendships) = 1, Poor (no friends, has acquaintances who are met in a group situation, such as work or a club) = 2, Very poor (no friendships involving selectivity & sharing) = 2. Independence: Full (able to cope with all self-care activities, travel independently & manage own finances without help) = 0, Moderate (requires some help in these areas) = 1, Little (significant help required) = 2. Autistic behaviours: ADI scores for unusual preoccupations; rituals/compulsions, resistance to change & unusual attachments to objects. Total score of 0/1 (None /minimal problems) = 0 Total score of 2-5 (Moderate problems) = 1 Total score of 6 (severe problems) = 2 Also measured was Education: university = 0, mainstream college = 1, special college = 2, no further education = 3; and Occupation: Regular paid work = 0, voluntary/special job arrangements = 1, day or residential centre = 2, no daytime placement = 3.
Howlin et al., 2004; Eaves & Ho, 2007; Farley et al., 2009 3 composite measures: Occupation, Friendships & Independent Living. Each rated 0, 1 or 2. Composite score (sum of above) comprising 5 levels: 0-2 = Very Good (achieving a high level of independence). 3-4 = Good (generally in work but requiring some degree of support in daily living). 5-7 = Fair (some degree of independence, although requires support & supervision does not need specialist residential provision) 8-10 = Poor (requiring special residential provision/high level of support). 11 = Very Poor (needing high-level hospital care). Occupation: employed or self-employed = 0, voluntary work/job training or low-pay scheme = 1, supported/sheltered employment = 2, in special centre/no occupation = 3. Friendships: range of scores from >1 close friendships involving sharing & exchange of confidences & range of different activities together = 0 to no friends, no joint activities = 3. Living independently = 0, in semi-sheltered accommodation (or still at home) but with high degree of autonomy = 1, living with parents, some limited autonomy = 2, in residential accommodation with some limited autonomy = 3, specialist autistic or other residential accommodation with little or no autonomy = 4, in hospital care or at home because nowhere else would accept the individual = 5. Support required: see Engstrom et al., 2003

Marriage et al., 2009

5 composite measures: Education, Vocation, Independence, Friendships & Intimate relationships. Each rated 1 (poor functioning) to 5 (age appropriate attainment).

Composite score (sum of above).

Education: Did not graduate from high school = 1, Graduated from an adapted program in high school = 2, Graduated from regular high school = 3, Attended college/university: If < 25 years, in college = 5, If > 25 years, attending college = 4, Graduated from college/university = 5.

Employment: Disability pension, never employed, not in educational program = 1, Employed briefly, unemployed now = 2, Series of jobs, briefly in or out of work now, or in school part-time, no job = 3, Stable employment or in school full-time, if >25 years = 4, Employed at potential or, if <25 & in school full-time = 5.

Living Arrangements/Independence: Lives with parents, needs support in activities of daily living & routine = 1, Lives with parents, needs some support to manage in community = 2, Lives with parents, self sufficient managing life otherwise, if >25 years = 3, Lives independently, needs some support to manage finances, etc. = 4, Living independently, manages affairs alone, or, < 25, lives with parents, manages affairs alone = 5.

Social Relationships (outside the family): Isolated, lives in own world, no friends = 1, Somewhat isolated, has some acquaintances–not necessarily any shared interests = 2, Some acquaintances around shared interests = 3, Has 1 or more friendships–only short term = 4, Has 1 or more close & enduring friendships = 5.

Intimate Relationships: No partner–ever, no interest = 1, Some attempt at finding partner, brief relationships, unsatisfactory to subject = 2, Relationships of a few months or more = 3, 1 or more long term (>6/12) relationships, or divorced = 4, Married/living common-law, satisfactory to both partners = 5.

Billstedt et al., 2005; Engstrom et al., 2003 (Lotter (1978) criteria).

Composite score comprising 5 levels:
Good outcome: a) employed or in education or training plus
b) living independently (for those aged 23 & over)
>2 friends or steady relationship (for those aged under 23).

Fair outcome: a) or b).

Restricted outcome (neither a) nor b) + no mental health problem).

Poor outcome (obvious severe handicap, no independent social progress, some clear verbal or non-verbal communicative skills).

Very poor outcome (obvious very severe handicap, unable to lead any kind of independent existence, no clear verbal or non-verbal communication).

Engstrom et al., 2003 Criteria for level of support

Public: None (no public support).
Low (advice & support from habilitation, regular home-help service).
Moderate (continuous home support, sheltered job, job assistant, regular support from psychiatry and/or habilitation.
High (supported living, group home or institution, daycentre, personal assistant).

Private: None (no contact with family).
Low (normal or near normal contact with parents, siblings & other relatives; support & practical assistance from time to time).
Moderate (regular practical assistance at home; daily contact by phone or physically; help with local authorities).
High (extensive help with social contacts & employment sites; total control of economic affairs; lives with relatives from time to time).

Appendix VI: Main study results

Results for 129 participants with and without a clinical diagnosis of ASD

Table VI.1: characteristics of the 129 participants recruited in to the study

		Clinical ASD N = 53	**Clinical no ASD N = 76**	
SCQ scores	Mean SCQ score (SD) Range	16.1 (4.7) 4 to 26	8.49 (5.8) 0 to 24	F(1,120)=60.4, p<0.001
	Exceeding cut-off for ASD (≥15)	32 (63%)	13 (19%)	$\chi 2(1)=24.6$, p<0.001
Age	Mean years (SD) Range	**36.2 (12.2)** **18 to 68**	**43.3 (11.9)** **20 to 64**	F(1,128)=11, p=0.001
Severity of ID	Mild Moderate Severe	23 (43%) 14 (26%) 16 (30%)	43 (57%) 18 (24%) 15 (20%)	$\chi 2(2)=2.57$, p=0.276
Gender	Males Females	42 (79%) 11 (21%)	52 (68%) 24 (32%)	$\chi 2(1)=1.85$, p=0.174
Ethnicity	Afro-Caribbean Asian White Unclear or other	20 (38%) 2 (4%) 28 (53%) 3 (6%)	24 (32%) 3 (4%) 47 (62%) 2 (3%)	$\chi 2(3)=1.53$, p=0.677
Type of residence	With family Residential Independently	**22 (42%)** 27 (51%) 4 (8%)	**16 (21%)** 45 (59%) 15 (20%)	$\chi 2(2)=8$, p=0.019
Psychiatric disorder	Present Absent	**25 (47%)** **28 (53%)**	**59 (78%)** **17 (22%)**	$\chi 2(1)=12.76$, p<0.000

Participants with and without a clinical diagnosis of ASD were sufficiently matched (there were no statistically significant differences between the groups) on severity of intellectual disability, gender and ethnicity. However, there were some significant differences between those with and without ASD:

- Participants with a clinical diagnosis of ASD were younger, more likely to live with family ($\chi^2(1)=6.29$, p=0.012) and less likely to have an additional psychiatric disorder.

Results for variables entered into the regression analyses

Table VI.2: Correlations between continuous dependent variables & age

		SCS	CANDID21 TotalNeed	HoNOSLD Total	DBC	Outcome Score
Age	Pearson Correlation	-.210	.065	-.215*	-.274**	.089
	Sig. (2-tailed)	0.04	.533	.033	.008	.396
	N	96	93	98	92	94

Table VI.3: ANOVAs of continuous dependent variables & socio-demographic/clinical variables

Dependent variable	Level of variable	N	Mean	SD	df	F	Sig
Mental health service consumption score	Female	27	11.11	11.7	1	5.039	. 632
	Male	69	9.16	10.5	94		
					95		
CANDID21 Total Need	Female	29	9.41	2.8	1	2.379	.126
	Male	64	10.39	2.8	91		
					92		
HoNOSLDTotal	Female	29	15.34	8.5	1	.007	.931
	Male	69	15.51	8.5	96		
					97		
DBC	Female	29	38.41	17.1	1	1.729	.192
	Male	63	44.00	19.7	90		
					91		
IndexOutcomeScore	Female	29	9.76	3.1	1	2.139	.147
	Male	65	8.83	2.7	92		
					93		
Mental health service consumption score	Afro-Caribbean	33	10.79	12.3	2	.495	.611
	White	56	8.80	9.9	93		
	Other/unclear	7	11.86	10.7	95		
CANDID21Total Need	Afro-Caribbean	30	9.83	3.1	2	.330	.720
	White	57	10.14	2.8	90		
	Other/unclear	6	10.83	1.7	92		
HoNOSLDTotal	Afro-Caribbean	34	16.00	10.4	2	.234	.792
	White	57	14.98	7.1	95		
	Other/unclear	7	16.71	8.9	97		
DBC	Afro-Caribbean	30	43.00	19.4	2	.143	.867
	White	56	41.50	19.4	89		
	Other/unclear	6	45.33	15.8	91		
IndexOutcomeScore	Afro-Caribbean	31	8.39	3.2	2	2.468	.090
	White	57	9.63	2.6	91		
	Other/unclear	6	8.00	2.3	93		
Mental health service consumption score	Inde	14	14.86	12.8	2	5.809	.004
	Resid	50	6.34	8.4	93		
	Family	32	12.72	11.6	95		
CANDID21Total Need	Inde	16	7.50	2.5	2	11.053	.000
	Resid	46	11.02	2.3	90		
	Family	31	10.03	3.0	92		
HoNOSLDTotal	Inde	16	12.56	6.4	2	3.245	.043
	Resid	50	14.54	8.6	95		
	Family	32	18.34	8.5	97		
DBC	Inde	16	28.00	9.5	2	9.390	.000
	Resid	46	41.30	18.6	89		
	Family	30	51.27	18.7	91		

Dependent variable	Level of variable	N	Mean	SD	df	F	Sig
IndexOutcomeScore	Inde	16	12.19	1.4	2	14.317	.000
	Resid	47	8.47	2.5	91		
	Family	31	8.52	2.9	93		
Mental health service consumption score	Mild	53	13.26	11.8	2	7.460	.001
	Moderate	26	4.62	5.5	93		
	Severe	17	6.41	9.8	95		
CANDID21Total Need	Mild	51	8.78	2.8	2	16.510	.000
	Moderate	25	11.28	2.2	90		
	Severe	17	12.24	1.4	92		
HoNOSLDTotal	Mild	55	12.85	7.3	2	11.788	.000
	Moderate	26	15.96	8.3	95		
	Severe	17	23.12	7.8	97		
DBC	Mild	50	37.84	19.7	2	3.893	.024
	Moderate	25	44.56	19.7	89		
	Severe	17	51.76	11.0	91		
IndexOutcomeScore	Mild	52	10.27	2.3	2	20.519	.000
	Moderate	25	8.84	2.7	91		
	Severe	17	6.00	2.4	93		
Mental health service consumption score	No diagnosis	34	6.35	9.3	1	5.322	.023
	Psychiatric disorder	62	11.55	11.2	94		
	Total	96	9.71	10.791	95		
CANDID21Total Need	No diagnosis	32	11.16	2.7	1	7.354	.008
	Psychiatric disorder	61	9.52	2.8	91		
	Total	93	10.09	2.9	92		
HoNOSLDTotal	No diagnosis	34	18.38	8.6	1	6.591	.012
	Psychiatric disorder	64	13.91	8.0	96		
	Total	98	15.46	8.4	97		
DBC	No diagnosis	32	48.16	13.9	1	4.962	.028
	Psychiatric disorder	60	39.08	20.6	90		
	Total	92	42.24	19.0	91		
IndexOutcomeScore	No diagnosis	32	7.34	2.8	1	23.117	.000
	Psychiatric disorder	62	10.03	2.4	92		
	Total	94	9.12	2.9	93		

Table VI.4: Correlations between continuous variables and CANDID scores

		HoNOSLD Total	DBC	Outcome Score
CANDID21TotalNeed	Pearson Correlation	.564**	.463**	-.545**
	Sig. (2-tailed)	.000	.000	.000
CANDID21MetNeeds	Pearson Correlation	.251*	.361**	-.401**
	Sig. (2-tailed)	.015	.000	.000
CANDID21UnmetNeeds	Pearson Correlation	.507**	.168	-.236*
	Sig. (2-tailed)	.000	.110	.023
CANDID21PropNeedsUnmet	Pearson Correlation	.366**	.033	-.077
	Sig. (2-tailed)	.000	.753	.466

Table VI.5: Chi-square tests between dichotomous dependent variables & other variables

		No psychotropic medication	Any psychotropic medication	Value	Df	p
Female	Count	1	28	3.951[a]	1	.05
	% within Gender	3.4%	96.6%			
Male	Count	13	56			
	% within Gender	18.8%	81.2%			
A/C	Count	6	28	1.483[a]	2	.476
	% within Ethnicity	17.6%	82.4%			
White	Count	8	49			
	% within Ethnicity	14.0%	86.0%			
Other	Count	0	7			
	% within Ethnicity	.0%	100.0%			
Inde	Count	1	15	2.562[a]	2	.278
	% within Residence	6.3%	93.8%			
Resid	Count	6	44			
	% within Residence	12.0%	88.0%			
Family	Count	7	25			
	% within Residence	21.9%	78.1%			
Mild	Count	9	46	.442[a]	2	.802
	% within SevID	16.4%	83.6%			
Moderate	Count	3	23			
	% within SevID	11.5%	88.5%			
Severe	Count	2	15			
	% within SevID	11.8%	88.2%			
No disorder	Count	11	23	13.879[a]	1	.000
	% within Psych dis	32.4%	67.6%			
Psychiatric disorder	Count	3	61			
	% within Psych dis	4.7%	95.3%			
		HoNOS-LD<22	**HoNOS-LD**	**Value**	**Df**	**p**
Female	Count	24	5	.429[a]	1	.513
	% within Gender	82.8%	17.2%			
Male	Count	53	16			
	% within Gender	76.8%	23.2%			
A/C	Count	25	9	1.236[a]	2	.539
	% within Ethnicity	73.5%	26.5%			
White	Count	47	10			
	% within Ethnicity	82.5%	17.5%			
Other	Count	5	2			
	% within Ethnicity	71.4%	28.6%			
Inde	Count	15	1	5.724[a]	2	.057
	% within Residence	93.8%	6.3%			
Resid	Count	41	9			
	% within Res	82.0%	18.0%			
Family	Count	21	11			
	% within Residence	65.6%	34.4%			
Mild	Count	47	8	8.255[a]	2	.016
	% within SevID	85.5%	14.5%			
Moderate	Count	21	5			
	% within SevID	80.8%	19.2%			
Severe	Count	9	8			
	% within SevID	52.9%	47.1%			
No disorder	Count	24	10	1.971[a]	1	.160
	% within psych dis	70.6%	29.4%			
Psychiatric disorder	Count	53	11			
	% within psych dis	82.8%	17.2%			

		DBC<51	DBC≥51	Value	Df	p
Female	Count	22	7	2.987[a]	1	.084
	% within Gender	75.9%	24.1%			
Male	Count	36	27			
	% within Gender	57.1%	42.9%			
A/C	Count	17	13	.778[a]	2	.678
	% within Ethnicity	56.7%	43.3%			
White	Count	37	19			
	% within Ethnicity	66.1%	33.9%			
Other	Count	4	2			
	% within Ethnicity	66.7%	33.3%			
Inde	Count	16	0	14.382[a]	2	.001
	% within Residence	100.0%	.0%			
Resid	Count	29	17			
	% within Residence	63.0%	37.0%			
Family	Count	13	17			
	% within Residence	43.3%	56.7%			
Mild	Count	35	15	4.537[a]	2	.103
	% within SevID	70.0%	30.0%			
Moderate	Count	16	9			
	% within SevID	64.0%	36.0%			
Severe	Count	7	10			
	% within SevID	41.2%	58.8%			
No disorder	Count	17	15	2.072[a]	1	.150
	% within psych dis	53.1%	46.9%			
Psychiatric disorder	Count	41	19			
	% within Psych dis	68.3%	31.7%			
		Ok outcome	**Poor outcome**	**Value**	**Df**	**p**
Female	Count	27	2	1.837[a]	1	.175
	% within Gender	93.1%	6.9%			
Male	Count	57	12			
	% within Gender	82.6%	17.4%			
A/C	Count	27	7	1.761[a]	2	.415
	% within Ethnicity	79.4%	20.6%			
White	Count	51	6			
	% within Ethnicity	89.5%	10.5%			
Other	Count	6	1			
	% within Ethnicity	85.7%	14.3%			
Inde	Count	16	0	5.880[a]	2	.053
	% within Residence	100.0%	.0%			
Resid	Count	44	6			
	% within Residence	88.0%	12.0%			
Family	Count	24	8			
	% within Residence	75.0%	25.0%			
Mild	Count	50	5	7.500[a]	2	.024
	% within SevID	90.9%	9.1%			
Moderate	Count	23	3			
	% within SevID	88.5%	11.5%			
Severe	Count	11	6			
	% within SevID	64.7%	35.3%			
No disorder	Count	25	9	6.313[a]	1	.012
	% within Psych dis	73.5%	26.5%			
Psychiatric disorder	Count	59	5			
	% within Psych dis	92.2%	7.8%			

TableVI.6: proportion of participants with specific psychiatric diagnoses receiving different medication

Psychiatric diagnosis/medication	ASD	No ASD
ADHD	N=3	N=1
ADHD	67%	100%
Anticonvulsant	33%	100%
Antipsychotic	67%	0%
Anxiety disorder	N=4	N=1
Antidepressant	50%	100%
Antipsychotic	50%	100%
Benzodiazepine	50%	0%
Bipolar disorder	N=5	N=9
No medication	0%	11%
Anticonvulsant	100%	67%
Antidepressant	0%	11%
Antipsychotic	40%	78%
Benzodiazepine	20%	0%
Mood stabiliser (lithium)	0%	33%
Depressive disorder	N=1	N=14
Anticonvulsant	14%	0%
Antidepressant	100%	100%
Antipsychotic	0%	21%
Anxiolytic	0%	7%
Benzodiazepine	0%	14%
Personality Disorder	N=0	N=1
Antidepressant		100%
Psychotic disorder	N=10	N=13
No medication	20%	0%
Anticonvulsant	10%	31%
Antipsychotic	80%	100%
Antidepressant	10%	8%
Benzodiazepine	10%	15%
Mood stabiliser (lithium)	10%	0%
Mixed anxiety & depression	N=0	N=2
Antidepressant		100%

Table VI.7: Associations between specific medication and measures

Measure	Medication	N	Mean	SD		Sum of Squares	df	Mean Square	F	Sig.
CANDID21 TotalNeed	Benzodiazepine	15	11.60	2.23	Between Groups	40.99	1	40.99	5.28	.024
	No benzodiazepine	78	9.79	2.88	Within Groups	706.32	91	7.76		
HoNOSLD Total	Benzodiazepine	15	19.93	10.13	Between Groups	354.54	1	354.54	5.18	.025
	No benzodiazepine	83	14.65	7.91	Within Groups	6569.80	96	68.44		
HoNBeh Subsc	Benzodiazepine	15	6.27	4.23	Between Groups	52.13	1	52.13	4.06	.047
	No benzodiazepine	83	4.24	3.46	Within Groups	1234.11	96	12.86		
DBCBeh	Benzodiazepine	15	36.40	10.35	Between Groups	864.06	1	864.06	4.19	.044
	No benzodiazepine	77	28.10	14.98	Within Groups	18556.77	90	206.19		

DBCBeh MinASD	Benzodiazepine	15	18.87	5.32	Between Groups	230.22	1	230.22	3.90	.051
	No benzodiazepine	77	14.58	8.04	Within Groups	5314.43	90	59.05		
Social functioning score	Benzodiazepine	15	7.60	3.02	Between Groups	41.07	1	41.07	5.26	.024
	No benzodiazepine	79	9.41	2.75	Within Groups	718.64	92	7.81		
Social functioning score	Antipsychotic	58	8.59	2.80	Between Groups	42.67	1	42.67	5.47	.021
	No antispychotic	36	9.97	2.78	Within Groups	717.04	92	7.79		
Social functioning score	Antidepressant	25	10.36	2.72	Between Groups	52.62	1	52.62	6.85	.010
	No antidepressant	69	8.67	2.79	Within Groups	707.09	92	7.69		
DBCBeh	Antidepressant	25	24.56	14.54	Between Groups	823.05	1	823.05	3.98	.049
	No antidepressant	67	31.28	14.31	Within Groups	18597.77	90	206.64		
DBCBeh MinASD	Antidepressant	25	14.52	7.63	Between Groups	19.96	1	19.96	.33	.570
	No antidepressant	67	15.57	7.91	Within Groups	5524.69	90	61.39		

Histograms and P-P plots for linear regression analyses

Total HoNOS-LD scores

Figure VI.1: Histogram of standardised residuals for total HoNOS-LD score linear regression

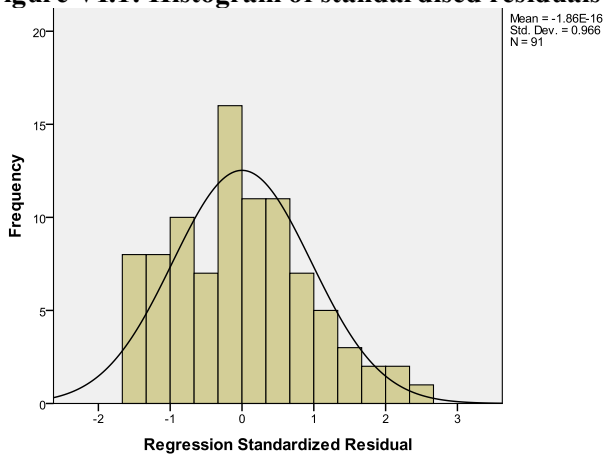
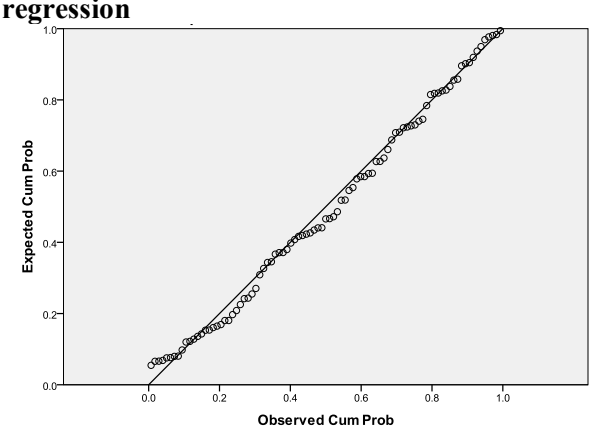


Figure VI.2: Normal P-P plot of standardised residuals for total HoNOS-LD score linear regression



TPBS on the Developmental Behaviour Checklist

Figure VI.3: Histogram of standardised residuals for TPBS linear regression

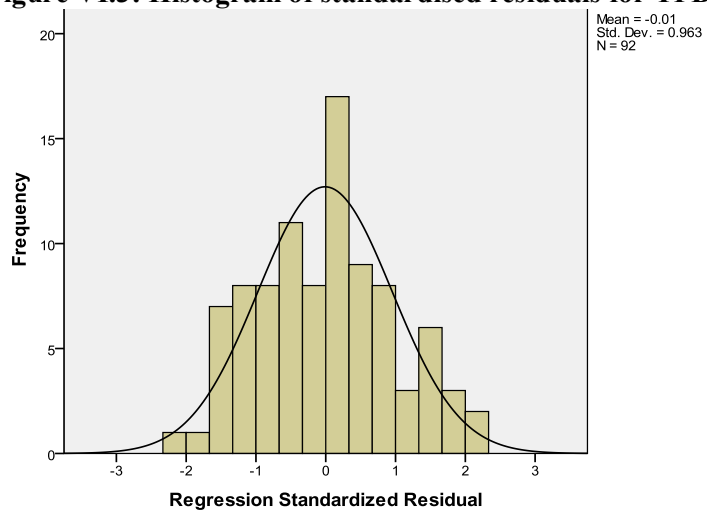
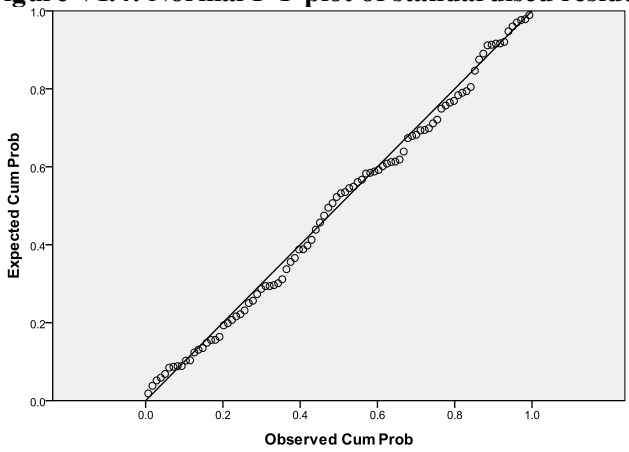


Figure VI.4: Normal P-P plot of standardised residuals for TPBS linear regression



Problem behaviour

Figure VI.3: Histogram of standardised residuals for DBC behaviour subscale linear regression

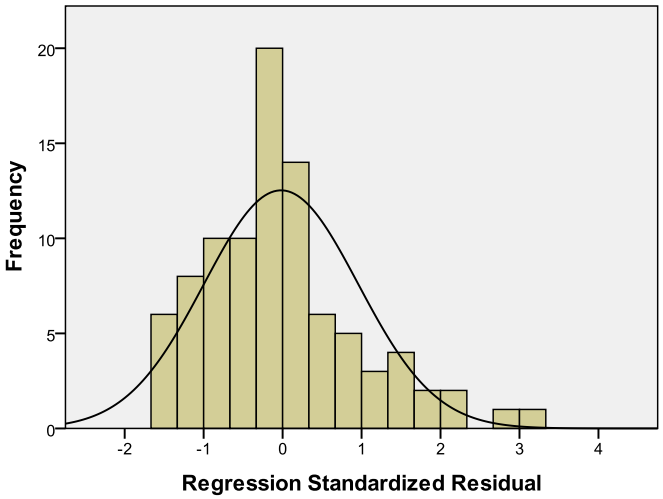


Figure VI.4: Normal P-P plot of standardised residuals for DBC behaviour subscale linear regression

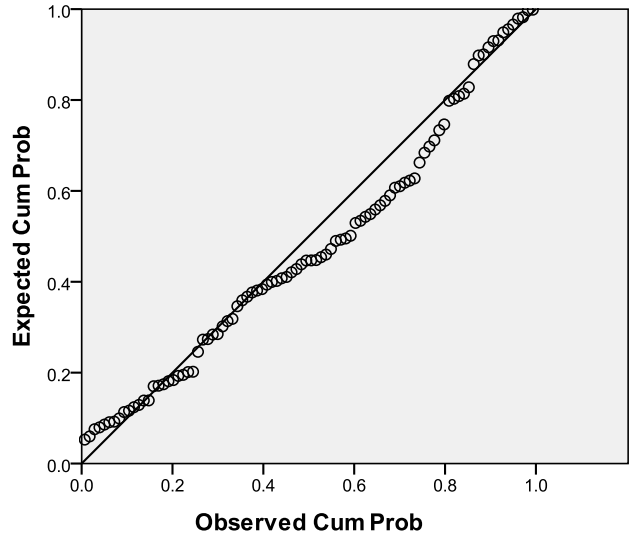


Figure VI.5: Histogram of standardised residuals for DBC behaviour subscale minus ASD items linear regression

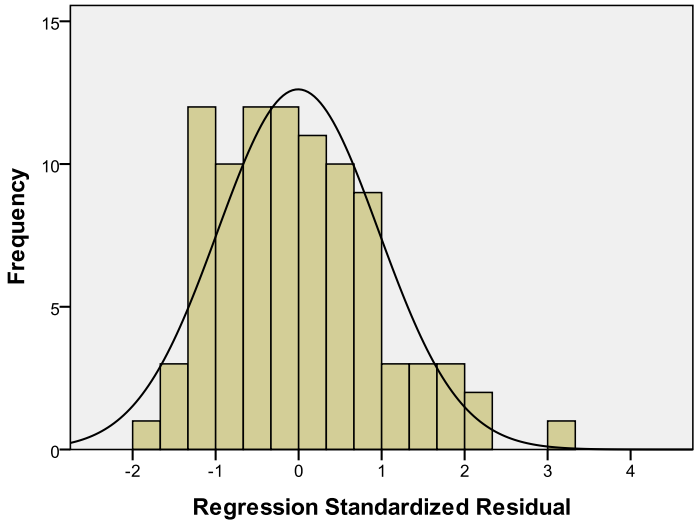
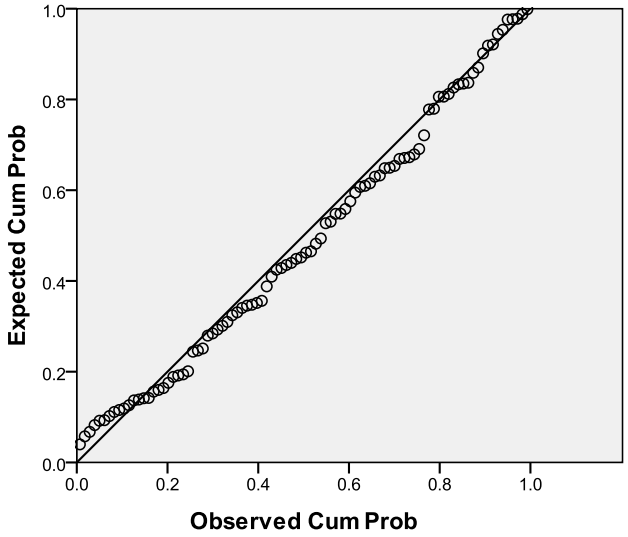


Figure VI.6: Normal P-P plot of standardised residuals for DBC behaviour subscale minus ASD items linear regression



Social functioning scale

Figure VI.9: Histogram of standardised residuals for the Social functioning scale linear regression

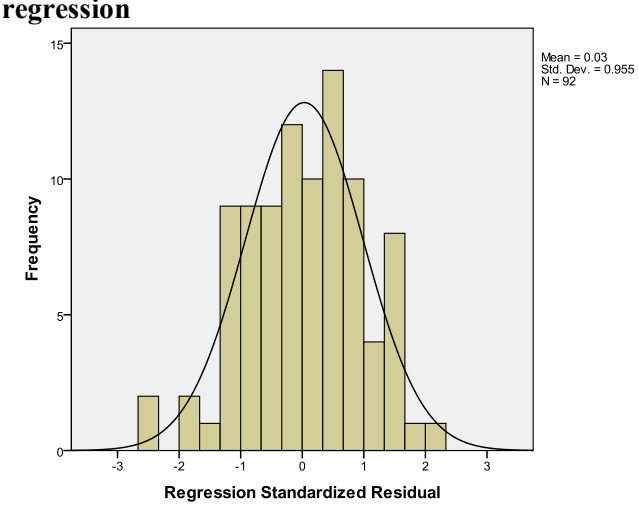
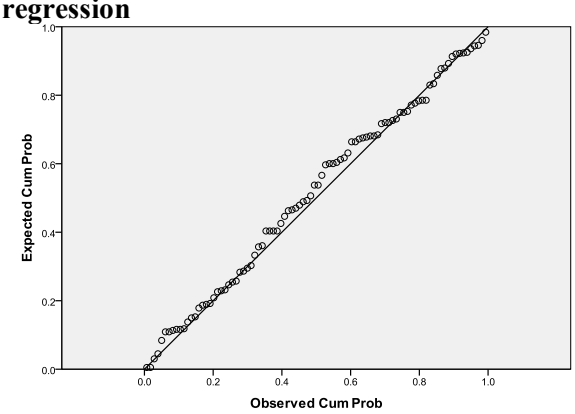


Figure VI.10: Normal P-P plot of standardised residuals for Social functioning scale linear regression



Developmental Behaviour Checklist subscales

Table VI.8: Items included in the DBC mental health subscale

Appears depressed, downcast or unhappy.	Mood changes rapidly for no apparent reason.
Bizarre speech. Please describe:	Moves slowly, underactive, does little, e.g. Only sits and watches others.
Cries easily for no reason, or over small upsets.	Not communicating as much as usual.
Delusions: has a firmly held belief or idea that can't possibly be true. Please describe:	Overactive, restless, unable to sit still.
Distressed about being alone.	Panics. Sweats, flushes, trembles.
Easily distracted from his/her task, e.g. By noises.	Sleeps too little. Disrupted sleep.
Excessively distressed if separated from a familiar person.	Sleeps too much or overly drowsy.
Fears particular things or situations, e.g. The dark, insects or crowds. Please describe:	Shy.
Has become confused or forgetful.	Says he/she can do things that he/she is not capable of.
Has become more withdrawn.	Sees, hears, something which isn't there.
Has nightmares, night terrors or walks in sleep	Hallucinations. Please describe:
Increase in appetite.	Talks about or attempts suicide.
Irritable.	Talks too much or too fast.
Lacks self-confidence, poor self-esteem.	Talks to self or imaginary people or objects.
Loss of appetite.	Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow.
Loss of enjoyment or interest in usual activities.	
Loss of self-care skills.	Tense, anxious, worried.
Makes gloomy statements.	Unrealistically happy or elated.

Table VI.9: Items included in the DBC behaviour subscale

Avoids eye contact. Won't look you straight in the eye. [ASD]	Overbreathes, vomits, has headaches or complains of being sick for no physical reason.
Aloof, in her/his own world. [ASD]	Overly attention-seeking.
Abusive. Swears at others.	Overly interested in looking at, listening to or dismantling mechanical things, e.g. Lawnmower, vacuum cleaner.
Arranges objects or routine in a strict order. Please describe: [ASD]	Poor sense of danger. [ASD]
Bangs head.	Prefers to do things on his/her own. Tends to be a loner. [ASD]
Becomes over-excited.	Preoccupied with only one or two particular interests. Please describe: [ASD]
Bites others.	Problems with cigarettes, alcohol or caffeine.
Cannot attend to one activity for any length of time, poor attention span. [ASD]	Problems with the illegal use of drugs.
Chews or mouths objects, or body parts.	Refuses to go to college, activity centre or workplace.
Covers ears or is distressed when hears particular sounds. Please describe:	Repeated movements of hands, body, head or face, e.g. Handflapping or rocking. [ASD]
Confuses the use of pronouns, e.g. Uses 'you' instead of 'I'.	Resists being cuddled, touched, or held by close friends or family. [ASD]
Deliberately runs away. [ASD]	Repeats back what others say like an echo.
Doesn't show affection.	Repeats the same word or phrase over and over. [ASD]
Doesn't respond to others' feelings, e.g. Shows no response if a close friend or family member is crying. [ASD]	Smells, tastes, or licks objects. [ASD]
Easily led into trouble by others.	Scratches or picks her/his skin.
Eats non-food items, e.g. Dirt, grass, soap.	Screams a lot. [ASD]
Facial twitches or grimaces.	Stares at lights or spinning objects. [ASD]
Flicks, taps, twirls objects repeatedly. [ASD]	Soils outside toilet though toilet trained, smears or plays with faeces.
Fussy eater or has food fads.	Speaks in whispers, high pitched voice, or other unusual tone or rhythm.
Gorges food. Will do anything to get food, e.g. Takes food out of bins or steals food.	Spits.
Gets obsessed with an idea or activity. Please describe: [ASD]	Switches lights on and off, pours water over and over; or similar repetitive activity. Please describe:
Grinds teeth.	Steals.
Has temper tantrums, e.g. Stamps feet, slams doors. [ASD]	Stubborn, disobedient or uncooperative.
Hides things.	Strips off clothes or throws away clothes.
Hits, bites or injures self.	Stands too close to others.
Hums, whines, grunts, squeals, or makes other non-speech noises. [ASD]	Tells lies.
Impatient. [ASD]	Throws or breaks objects. [ASD]
Inappropriate sexual activity with another.	Tries to manipulate or provoke others.
Impulsive, acts before thinking.	Underreacts to pain.
Jealous.	Unusual body movements, posture or way of walking. Please describe:
Kicks, hits or injures others.	Upset or distressed over small changes in routine or environment. Please describe: [ASD]
Laughs or giggles for no obvious reason. [ASD]	Urinates outside toilet, although toilet trained.
Lights fires. [ASD]	Very bossy.
Likes to hold or play with an unusual object, e.g. String, twigs, overly fascinated with something, e.g. Water. [ASD]	Wanders aimlessly. [ASD]
Masturbates, or exposes self, in public.	Whines or complains a lot.
Noisy or boisterous.	
Overaffectionate.	

[ASD] = items included in the DBC-P ASD subscale and removed from the behaviour subscale in some analyses

Psychotropic medication, psychiatric disorders and physical health problems

Table VI.10: psychotropic medication included in Tables 9.33, 9.45, VI.6 and VI.7

Type of medication	Name of medication
Antipsychotic	Amisulpride, Aripiprazole, Benperidol, Chlorpromazine, Clopixol, Clozapine, Flupentixol, Haloperidol, Olanzapine, Quetiapine, Risperdone, Trifluoperazine, Zuclopenthixol
Anticonvulsant	Buccal Midazolam, Carbamazepine, Clobazam, Clonazepam, Depakote, Gabapentin, Lamotrigine, Rufinamide, Sodium Valproate, Topiramate
Antidepressant	Amitriptyline, Citalopram, Clomipramine, Escitalopram,,Fluoxetine, Fluvoxamine, Mirtazapine, Paroxetine, Sertraline, Trazodone
Anxiolytic	Zopiclone
Stimulant (ADHD)	Atomoxetine, Equasym XL, Methylphenidate
Mood stabiliser	Lithium Carbonate
Benzodiazepine	Diazepam, Lorazapam, Temazepam

Table VI.11: diagnoses included in each category of psychiatric disorder in Table 9.8

Type of disorder	Diagnostic label as entered into mental health record
ADHD	ADHD
Anxiety disorder	Anxiety disorder, Generalised Anxiety Disorder, OCD, Other anxiety disorder, PTSD
Bipolar disorder	Bipolar affective disorder, Bipolar disorder
Depression	Depressive episode, Mild depressive disorder, Moderate depressive episode, Persistent mood (affective) disorder, Recurrent depression, Recurrent depressive disorder, Recurrent depressive episode
Personality disorder	Emotionally unstable Personality disorder (Borderline type)
Psychotic disorder	Organic delusional disorder, Organic Psychotic disorder, Paranoid schizophrenia, Psychotic disorder, Psychotic episode, Schizoaffective disorder, Schizophrenia, Unspecified psychotic illness
Other	Affective & anxiety disorder, Mixed anxiety & depression, Oppositional Defiant Disorder

Table VI.12: physical health problems and disabilities included in Table 9.26

	ASD	No ASD
Angular stomastis	1	0
Arthritis	0	3
Asthma	2	4
Cardiomyopathy	0	2
Cerebral palsy	1	1
Diabetes (or glucose intolerance)	4	8
Dyspraxia	1	0
Fibromyalgia	0	1
Haemophillia	0	1
Hemiplegia	1	0
Heptatitis B+	1	1
Hiatus hernia	0	0
Hypercholesteroleamia	0	1
Hypertension	1	10
Irritable bowel syndrome	0	1
Multiple sclerosis	0	1
Pulmonary embolism	0	1
Sickle cell trait	1	0
Spina bifida	1	0
Thalassaemia	1	0
Thyroid problems	1	4
Number with ≥1 of these problems	**15 (30%)**	**26 (54%)**

Appendix VII: Additional calculations

Estimated rate of ASD

Rates of clinically diagnosed ASD=33.5%: 20% of those with mild ID, 42% of those with moderate ID and 67% of those with severe ID.

Proportion of service users with mild ID=56%, moderate ID=29%, severe ID=15%.
Overall rate of those with ASD and each severity: 11%, 12.1% and 10.4%

Rate of ASD traits=8.7% of those with mild ID, 8.8% of those with mod ID & 4.9% of those with severe ID. Overall rates of 4.8%, 2.5% & 0.8%=8.1%; revised ASD prevalence=41.6%

Standardised data suggested that: 13% of those with mild ID & a clinical diagnosis of ASD don't have ASD => rates of ASD & mild ID =11% – 0.13x11=9.6%; revised prevalence=40.2%

Rate of ASD behaviours among those with no clinical diagnosis of ASD: 18.6% of those with mild ID, 33.3% of those with moderate ID & 93.3% of those with severe ID => overall rates of 7.4%, 4.8%, 4% = 16.2% => overall prevalence of ASD = 40.2 + 16.2 = 56.4%.